Margo Edmunds · Christopher Hass
Erin Holve *Editors*

Consumer Informatics and Digital Health

Solutions for Health and Health Care

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Editors
Margo Edmunds
Washington, DC, USA

Christopher Hass
Boston, MA, USA

Erin Holve
Takoma Park, MD, USA

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Foreword

This book exemplifies an exciting and opportunistic development toward improving human health, and it deserves your attention. In short, *Consumer Informatics and Digital Health* seeks to review the evidence base for consumer engagement and consumer informatics approaches; offer expert advice and also report on many examples of innovations using data analytics and digital health strategies in clinical, community-based, and home-based settings; and illustrate ways in which health systems are using informatics approaches to make a difference both in personal as well as population and community health.

In addition to providing practical information grounded in computer science, telehealth, and the early days of mobile health, several authors offer their perspectives with respect to policy, ethical, and organizational dimensions of digital technologies and consumer engagement. Margo Edmunds and her co-editors and contributors demonstrate a commitment to creating a more informed, expert, consumer-centered workforce. Together, the chapters demonstrate the diverse disciplines that must work together in teams to facilitate transformation in health care. Highly motivated consumers also can get value from the book by finding real-world examples of strategies to engage providers in shared decision-making regarding their own and their family members' health.

A review of some relevant history might offer readers additional insights into the fresh perspective amply demonstrated by the book's editors and contributors, particularly with respect to core concepts such as patient centeredness, social determinants of health, and health equity. In 1991, the Institute of Medicine released its report, *The Computer-Based Patient Record: An Essential Technology for Health Care*. One committee member, Morris Collen, argued effectively to the committee that the "new" record was not simply a computer-based version of the "old" paper medical record. The focus of this new record was not to be on medicine or physicians or nurses or other clinicians, but instead centered on the individual patient and, collectively, patient populations. Around the same time, Kerr White and Julia Connolly (1991) noted that the chasm between personal health and public health needed to be bridged by reorienting medical education to consider population health.

Even earlier, in the 1960s and 1970s, Larry Weed, another early giant in the field of health-related informatics, spoke eloquently on the critical importance of listening to the patient and constructing a problem list generated as much from the patient as from the caregivers, presaging the focus on patient-reported outcomes as well as social determinants of health. From Weed's perspective, if the problem was transportation or food, it was a problem that deserved identification and attention (Weed 1975)—a perspective borne out by the current literature.

When the *Crossing the Quality Chasm* report of the IOM appeared in 2001, equity made the list of needed attributes of quality health care systems. Ironically and regrettably, however, equity was listed last among the six attributes. Having been a member of the committee that produced the report, all one can say is that the ordering revealed a cruel irony of thinking at that time. Clearly, if equity isn't the first consideration, no level of quality of care will help those who cannot access care. It is encouraging that Edmunds and her contributors seem to have taken that perspective to heart in *Consumer Informatics and Digital Health* and have addressed social and economic risk factors, health disparities, and health equity throughout the book.

Moving forward to today, biomedical and health informatics continue to evolve at a rapid pace as the dimensions of the discipline both widen and deepen. Happily, the past two decades have shown explosive growth in the availability of and access to computer-based health records for health professionals, patients, and citizens. As health information and communications technology and platforms for health-related information and knowledge have improved dramatically, access of consumers to their own health care data is finally beginning to become a reality. Health information technology is now capable of collecting and sharing more detailed history between patients, caregivers, and providers. In addition, informatics enables us to discern individual and population-based patterns to better understand the impact of social determinants and strategies to promote health equity.

After decades of knowing that "activated" users reduce personal suffering and help reform aspects of system underperformance leading to greater equity, quality, and safety at reduced cost, patients still have a residual and insufficient power disadvantage when it comes to patient-centered care. Despite the efforts of consumer advocacy groups, the Institute of Medicine/National Academy of Medicine, and many others to enhance the policy and practice environment and dramatically enhance secure access to personal health information for clinical care and research, the acceptance of activated consumers lags far behind our early vision and even realistic expectations.

The vision of transitioning from an excessively medical mindset to one with shared decision-making and a consideration of all the social determinants of illness and disease is most worthy. These contributors should be commended for their strong effort to promote the role of consumer informatics in this transition.

The technology has arrived to facilitate the vision of equitable, patient-centered care envisioned by White, Connolly, Weed, and many others. As Thaler and Sunstein remind us, we now need policy to help "nudge" us toward health, wealth, and happiness. *Consumer Informatics and Digital Health* offers a vision of ways technology

can support person-centered health that should spur us on toward this goal. We'll know we've made progress when the nation understands and embraces the importance of health data generated by patients and health system records, and this pressure is coming from sectors of the population seeking better health status for all individuals and all communities.

Charlottesville, VA Don Eugene Detmer

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Preface

When our editorial team first started planning this book in response to Springer's invitation, we were exhilarated and daunted at the same time. Each of us has deep, diverse experience in health consumer technologies, mobile health, electronic health data, telehealth, informatics, and user experience. We had worked together before and were excited to bring our breadth of practical experience to the literature on consumer health informatics. At the same time, we were aware of the challenge of staying ahead of the curve given the fact that the digital health industry moves really fast; is often referred to as "the wild west;" and that the hype cycle can overwhelm promising health information technology.

We knew it would be challenging to keep up with new developments in health care delivery while finding a way to contribute to a systematic evidence base for consumer-focused technology interventions. And we didn't want the book to be out of date before it was even published!

In response, we started by defining the audiences we most wanted to reach with *Consumer Informatics and Digital Health*: the next generation of people who want to design, test, implement, study, and use consumer-facing technologies in health and health care. Then we began reaching out to our colleagues and friends who are already part of this multi-sector ecosystem in some way, since so many are teaching, training, and mentoring the future workforce, and we asked them to write chapters. The book's authors are based in academic institutions, think tanks, design firms, health systems, government, industry, and community-based and consumer settings. They are consumers, physicians, nurses, psychologists, data scientists, informaticians, designers, developers, and systems thinkers who share an interest in making health systems better for consumers, patients, their families, communities, and the professionals and citizens who work with them and on their behalf. The contributors are not armchair theorists; rather, they are actively engaged in a range of activities to design, develop, and implement consumer health informatics.

We asked the authors to use a similar chapter structure to help organize their thoughts and to make the book easier to read in its entirety. We also invited them to think of their chapters as individual contributions that can stand apart from the rest of the book, while relating to the other chapters. One hallmark of the book is a

shared commitment to thinking through new areas of consumer health informatics in which more innovation and more evidence is needed. Some chapters are more focused on the evidence base, while others focus on practical issues in design and implementation, and some are more policy-oriented, but all include some thinking about the future evolution of their topic.

Consumer Informatics and Digital Health presents and reviews organizational, technical, policy, design, and implementation issues associated with consumer-facing technologies such as websites, consumer portals, wearables, applications (apps), devices, and social media that are engaging people in health and health care experiences.

The first part, Foundations of Consumer Informatics and Mobile Health, includes four chapters on consumer engagement, consumer informatics and digital health, using Health IT and data analytics to support health equity, and the trends and new directions for social media and online consumer tools.

The second part, A New Ecosystem for Development and Design, has five chapters on the fundamentals of usability and user-centered design; health innovation trends; the importance of accessibility, especially for people with disabilities; practical suggestions for doing usability and utility testing; and motivational design and persuasive technology for behavior change.

In the third part, on Consumer-Centered and Consumer-Generated Information, five chapters review the evidence base for consumer-generated information using visualization, digital tools for parents, mobile health, cancer informatics, and content strategy.

Part IV, Policy and Regulatory Issues, has five chapters on value-based purchasing, community health, ethics, open science and data analytics, and how the National Health Service in the United Kingdom developed its digital health strategy.

In our final chapter, we review some of the social, technical, and industry trends affecting the consumer informatics field and anticipate how they may play out in the future.

We hope that readers will find that the book represents consumer health informatics as we see it—a rapidly evolving, multi-sector, team-oriented ecosystem. We also hope that the book may help to attract new talent in research, policy, clinical practice, population health, design, data science, and informatics, along with entrepreneurs, investors, and other stakeholders.

We are honored and grateful to the authors for their contributions. We find them to be an unusually talented, committed, and creative group who shared information easily and were generous with their time.

We also would like to thank the people who spoke with us on background, reviewed chapters, provided assistance with graphics, and helped in other ways. In alphabetical order, they are Lauren Adams, Thomas Blount, Patricia Flatley Brennan, Minhee Cho, Vineet Chopra, Catherine Craven, Stephanie Creel, Gregory Downing, DaShawn Groves, Hank Fanberg, Charles Cinque Fulwood, Sarah Greene, Tanya Hamburger, Laurie Beth Harris, Andrew Ibrahim, Beth Henry Johnson, Kyu Kang, Elizabeth Koechlein, Lisa Lang, Joy Lewis, Bernadette Loftus, Aileen McHugh, Lois Olinger, Anna Paladini, Douglas Peddicord, Gabbi Promoff,

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Washington, DC, USA — Margo Edmunds
Boston, MA, USA — Christopher Hass
Takoma Park, MD, USA — Erin Holve

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Contents

Contributors

David K. Ahern Digital Behavioral Health & Informatics Research Program, Brigham & Women's Hospital, Boston, MA, USA

Adriana Arcia School of Nursing, Columbia University, New York, NY, USA

Suzanne Bakken School of Nursing and Department of Biomedical Informatics, Columbia University, New York, NY, USA

Ellen Beckjord Insurance Services Division, University of Pittsburgh Medical Center, Pittsburgh, PA, USA

Mandi Bishop Gartner, Jacksonville, FL, USA

Ronald L. Copeland Kaiser Permanente, Oakland, CA, USA

Dustin DiTommaso Mad*Pow, Boston, MA, USA

Rhode Island School of Design, Providence, RI, USA

Margo Edmunds AcademyHealth, Washington, DC, USA

Kari Gali Express Care Online, Distance Health Cleveland Clinic, Cleveland, OH, USA

Patient Safety Leadership Program, University of Illinois Chicago, Chicago, IL, USA

M. Christopher Gibbons Johns Hopkins University School of Medicine and The Greystone Group, Inc., Washington, DC, USA

Christopher Hass Boston, MA, USA

Bradford Hesse Health Communication and Informatics Research Branch, National Cancer Institute, Bethesda, MD, USA

Erin Holve Department of Health Care Finance, Government of the District of Columbia, Washington, DC, USA

Susan C. Hull Gartner, Inc. Stamford, CT, USA

Sakib Jalil University of California, Davis, Sacramento, CA, USA

Jason Jones Kaiser Permanente, Oakland, CA, USA

Katherine K. Kim University of California, Davis, Sacramento, CA, USA

Juergen Klenk Deloitte Consulting LLP, Arlington, VA, USA

Jacqueline A. Merrill School of Nursing and Department of Biomedical Informatics, Columbia University, New York, NY, USA

Victoria Ngo University of California, Davis, Sacramento, CA, USA

Philip R. O. Payne Informatics Institute and Division of General Medical Sciences, School of Medicine, Washington University, St. Louis, MO, USA

Carolyn Petersen Mayo Clinic, Rochester, MN, USA

Mordechai D. Raskas Division of Telemedicine and Clinical Informatics, PM Pediatrics, Greenbelt, MD, USA

Madeleine A. Rothberg The Carl and Ruth Shapiro Family National Center for Accessible Media at WGBH Educational Foundation, Boston, MA, USA

Dana Aronson Schinasi Division of Emergency Medicine, Emergency Care Connect, Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University Feinberg School of Medicine, Evanston, IL, USA

Yahya Shaikh Johns Hopkins University School of Medicine and The Greystone Group, Inc., Washington, DC, USA

Rasu Shrestha UPMC and UPMC Enterprises, Pittsburgh, PA, USA

Julian C. Tomlins Roche Products UK Ltd, London, UK

Shayan Vyas Critical Care Medicine, Nemours Children's Hospital, University of Central Florida, College of Medicine, Orlando, FL, USA

John Wilbanks Sage Bionetworks, Washington, DC, USA

Winston F. Wong Kaiser Permanente, Oakland, CA, USA

About the Editors

Margo Edmunds, PhD is Vice President, Evidence Generation and Translation at AcademyHealth, where she oversees a portfolio of projects on information infrastructure, research translation, dissemination, and health communications. Her expertise includes informatics and communications technology policy, health information exchange, and web-based learning and communications tools.

Christopher Hass is a consulting UX strategist, presenter, and past president of UXPA International and its Boston Chapter. He is an expert on the subjects of human-centered design, accessibility, UX research, and the development of innovative products and services for a wide variety of commercial and government clients.

Erin Holve, PhD, MPH, MPP is Director, Health Care Reform and Innovation, Department of Health Care Finance, the Government of the District of Columbia. Previously, she was the Principal Investigator for the EDM Forum, a federally funded innovations collaborative, and led projects on comparative effectiveness research and patient-centered outcome research. She also managed online learning and professional development activities.

Part I
Foundations of Consumer Informatics and Mobile Health

Chapter 1
Promoting Consumer Engagement in Health and Health Care

Margo Edmunds

Introduction: Converging Influences and Larger Trends

Until relatively recently, consumer health information was provided primarily by highly trained professionals who were associated with privilege and personal wisdom and experience. Gradually, there has been increasing interest in relying more on the best available evidence, professional standards of care, and personally generated information from patients and consumers (Emanuel & Pearson, 2012; Fried, 2016).

Consumer and patient engagement in health and health care was greatly enabled when personal computers became available in the mid-1980s and the Internet began to make it possible for more people to exchange information outside of their work environments. Health-related websites such as WebMD™, healthfinder.gov, and others began to give consumers direct access to professional medical journals as well as information that was translated and synthesized for lay people, allowing them to learn about their own and their family members' medical diagnoses and conditions (Brennan & Safran, 2005; Lober & Flowers, 2011). Consumers also started some of the earliest web sites to share their personal experiences managing their own chronic conditions, such as asthma and diabetes, and online communities grew around these common concerns and goals.

As a result of gaining direct access to medical information, many people started asking their clinicians how to interpret contradictory findings from different studies, how to know what treatment and prevention strategies would work best for them, and how they could learn more about managing their own health conditions. The reaction from the clinical community was decidedly mixed (see, for example, Brennan & Safran, 2005; Hoch & Ferguson, 2005), but evidence was already available from a variety of sources that meaningful patient engagement can lead to better health outcomes (Kaplan, Greenfield, & Ware, 1989; Lorig, 2014).

M. Edmunds (✉)
AcademyHealth, Washington, DC, USA

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The question was, and still is, how to move beyond just adhering to prescription schedules and basic recommendations about nutrition and physical activity into effectively engaging and supporting patients and consumers in managing their health and illness across the continuum of care. We believe this happens most naturally and effectively when clinicians are meaningfully engaged in shared decision-making with patients, families, and caregivers (Elwyn et al., 2012), and when mutual engagement is supported by electronic tools such as personal health records, portals, decision aids, and communications technologies, such as smartphones and videoconferencing.

This chapter opens with highlights of health policy discussions on consumer engagement; traces the co-development of consumer informatics and consumer technologies, including digital health tools; describes the importance of reaching consumers with health messages in their communities; and concludes with a discussion of emerging trends and future opportunities to transform health care through consumer engagement and digital health.

Health Information Technology Policy and Quality of Care

The Institute of Medicine memorialized evidence about the importance of consumer engagement in its landmark 2001 report *Crossing the Quality Chasm* (IOM, 2001), which was part of a 10-year commitment to guide improvements in the quality of health care and address growing public concern about medical errors and patient safety. Recognizing the role of information and communications technology in redesigning health care, the IOM report recommended that system redesign should include continuous provider–patient relationships with 24/7 and virtual access; shared decision-making, with decision support tools (materials that can be consulted for more information); "unfettered access" to personal health information and clinical knowledge; proactive anticipation of patient needs; and coordination of care among cooperating clinicians (IOM, 2001; See Table 1.1).

Partially because health IT systems were not well developed at the time, the IOM's twenty-first century design rules were overshadowed by the blockbuster recommendation elsewhere in the same report that health care should be "safe, effective, patient-centered, timely, efficient, and equitable" (Tang & Lansky, 2005). That recommendation unleashed a storm of protest from organized medicine and hospital groups, but it also started a national discussion about more active engagement of patient and consumer groups that led to the inclusion of consumers in federal advisory bodies such as the American Health Information Community (AHIC), chartered in 2006, and many other groups.

Another, largely separate, national conversation initiated at about the same time by a different IOM report was about acknowledging racial and ethnic disparities in health due to systemic differences in access to care, quality of care, and social and

Table 1.1 These 10 design principles were recommended by the Institute of Medicine in 2001

Ten rules for redesigning the healthcare system
1. Care is based on continuous healing relationships
2. Care is customized according to patient needs and values
3. The patient is the source of control
4. Knowledge is shared and information flows freely
5. Decision-making is evidence-based
6. Safety is a system property
7. Transparency is necessary
8. Needs are anticipated
9. Waste is continuously decreased
10. Cooperation among clinicians is a priority

According to the IOM report, "information technology, including the Internet, holds enormous potential for transforming the health care delivery system, which today remains relatively untouched by the revolution that was swept nearly every other aspect of society" (Source: Institute of Medicine/National Academy of Medicine *Crossing the Quality Chasm* report, National Academies Press, 2001. Executive Summary, Recommendation 4).

environmental determinants of health (IOM, 2002a). The congressionally requested disparities report, entitled "Unequal Treatment," provided extensive documentation of inequities in quality of care, noting that people of color not only had the expected fears and stress about medical treatment for illness and disease but also had to think about "whether their race or ethnicity will affect the kind of care they receive" (IOM, 2002b).

The bodies of evidence about patient activation and engagement and disparities have continued to grow, beginning with support from the Agency for Healthcare Research and Quality and the National Institutes of Health (NIH) (e.g., Greene, Hibbard, Sacks, & Overton, 2013; Hibbard & Greene, 2013). Funding from the Patient-Centered Outcomes Research Institute (PCORI) and the Center for Medicare and Medicaid Innovation (CMMI), both created in the Affordable Care Act (CMS.gov, 2017; Dayoub, 2014), has increased the focus on best practices in using consumer technology and telehealth to support care and eliminate health disparities that arise from social determinants of health, such as income, food security, and differential exposure to environmental risks. Significant investments from the Robert Wood Johnson Foundation, The W. K. Kellogg Foundation, The Kresge Foundation, The California Healthcare Foundation, and other philanthropies have also added to the evidence base about consumer empowerment and social and environmental factors in health.

The Democratization of Health Care

In some circles, patient engagement has been compared to a "blockbuster drug" because of its power to transform care, even if it "should have formed the heart of health care all along" (Dentzer, 2013). Another sign of the times for consumer engagement and shared decision-making is the recent National Academy of Medicine (NAM, formerly the IOM) discussion paper on the democratization of health care (Tang et al., 2016). Democratization means that people "must have a powerful voice and role" in their own health decisions, and that "health professionals and institutions must value social equity" and treat people as individuals, not merely as patients, in a person-centered health care ecosystem (p. 1).

The upswing in consumer informatics reflects an ongoing cultural shift within healthcare systems and among providers from paternalism to partnerships. In situations where there are choices to be made about which course of treatment to pursue, shared decision-making can help to ensure that clinical decisions are both evidence-based and aligned with patient and family preferences and values (Lee & Emanuel, 2013).

Clearly, people's engagement in their own health and health care would not be possible without easy-to-use digital tools such as websites, consumer portals, smartphones, and sensor-based devices that promote personalized remote monitoring, improve connectivity with clinicians and health systems, and help inform patients and families about care options. Without the Internet and years of investments in broadband to build local communications infrastructure, online communities and social networks could not have had such a major impact on patient activation among individuals and families managing chronic and acute care episodes.

Similarly, without a national investment in health information exchange and the implementation and adoption of electronic health records (EHRs), health care providers would not be able to support virtual visits (telehealth), consumer portals, e-prescribing, online scheduling, or other tools that promote convenience, reduce burden, and even improve accuracy of reporting. One of the major challenges health systems face is the need to integrate consumer-generated personal data with their providers' medical records (Detmer, Bloomrosen, Raymond, & Tang, 2008; Sittig & Singh, 2010).

In sum, the remaining challenges for truly shared decision-making and person-centered care are partly technological, but they are also heavily influenced by organizational and professional cultures and leadership, the views of the local provider community, and views about designing systems for people, or person-centered design (Barry & Edgman-Levitan, 2012), including the acknowledgement of racial, ethnic, and cultural differences. At this writing, in our view, there are only a few health systems that truly consider the patient and family experience as an integral part of the ecosystem of care, and part of their responsibility, including the need to be respectful and competent regarding racial and ethnic diversity. With increasing awareness, discussion, and thought leadership, we hope and expect that many more will be moving in this direction in the coming months and years (see Fig. 1.1).

Fig. 1.1 The Agency for Healthcare Research and Quality (AHRQ) and the Ad Council partnered on a 2011 campaign to improve communication between clinicians and patients. Source: AHRQ/ Ad Council Patient Involvement Health Care Provider Campaign. The Agency for Healthcare Research and Quality. August 2011. Used with permission

The Consumer Movement and Person-Centered Care

Consumer Informatics

Since about 2000, the term consumer health informatics has been used by professionals in academic medical centers and health systems to refer to the study of people's ability to access information, participate in evidence-based care, and control their health through partnerships supported by information and communications technology (Eysenbach & Jadad, 2001; Eysenbach et al., 2002; Kaplan & Brennan, 2001).

Within the multidisciplinary science of informatics, consumer informatics is one of the five basic areas of application, along with clinical informatics, clinical research informatics, public health informatics, and translational informatics (AMIA, 2017, https://www.amia.org/about-amia/science-informatics). Additional informatics divisions are based on professional domains (e.g., medicine, nursing, dentistry, and pharmacy) or practice settings (e.g., health sciences, imaging).

At the time the term consumer informatics initially came into use, provider–patient relationships were beginning to be influenced by broader trends that were sweeping other industries, particularly e-commerce and the use of the ATM (automated teller machine) by the financial services industry (Sittig & Singh, 2010). Shifting consumer expectations about responsive technology and portable records in health care were no match for the entrenched, paper-based legacy systems that had grown out of fee-for-service medicine and billing for every clinical encounter. It literally took an act of Congress in 2009 (HITECH) to provide financial incentives for hospitals and group practices to "get out of paper" and adopt electronic health records, a process which is still underway and being closely watched and studied (e.g., Buntin, Burke, Hoaglin, & Blumenthal, 2011; DeSalvo & Washington, 2016; Edmunds, Peddicord, & Frisse, 2016).

One challenge in this still-emerging field of consumer informatics is the sheer number of terms associated with it. Some terms refer to the consumer side, others to the provider side, and still others to the technology that brings them together. In addition to the term consumer health informatics, or consumer informatics, several terms are used in broader related areas of industry and health policy and practice, including connected health (Partners HealthCare Connected Health, n.d.); consumer Health IT (AHRQ, 2016; HIMSS, 2014; National Research Council, 2011); digital health (Rock Health, 2015); e-Health (ASPE, 2016; Eysenbach, 2001); e-Patient (e.g., Hoch & Ferguson, 2005); i-Health (Island Health, 2017); mobile health (mHealth) (Atienza & Patrick, 2011); telehealth (e.g., Kvedar, Coye, & Everett, 2014); and virtual visits (Gordon, Adamson, & Kurklinsky, 2017) (see Table 1.2).

These terms are not interchangeable: each focuses on a different part of the consumer/patient experience of technology-supported communications and has its own constituencies and user groups. A more standardized, accepted vocabulary would help to enhance the field's visibility and reduce the confusion that currently characterizes it (Gibbons & Hoyt, 2014).

Table 1.2 Web presence varies substantially for different terms in digital health

Term	Google results on May 4, 2017
Digital health	148,000,000
Consumer Health IT	16,900,000
Connected health	16,000,000
e-Patient	9,040,000
e-Health	8.550,000
i-Health	4,910,000
Telehealth	3,870,000
Health IT	3,250,000
mHealth	2,270,000
Consumer informatics	907,000

Source: Google search conducted by the author on May 4, 2017

Despite the lack of public visibility and funding for research, consumer informatics has continued to evolve at the intersection of people and technology. In 2011, a systematic review of consumer health informatics studies found enough evidence to recommend that future clinical practice should integrate "patient-oriented technology-based" supports for health information and health behavior change, and that researchers should learn more about how different tools work for different groups, such as children, the elderly, and medically underserved individuals, including racial and ethnic minorities (Gibbons et al., 2011; Kesselman, Logan, Smith, Leroy, & Zeng-Treitler, 2008).

It's also clear that future informatics studies should focus on better tailoring messages, personalizing information, and embedding feedback on personal progress into the digital tools (Gibbons & Hoyt, 2014). These approaches are both evidence-based and time-honored traditions in the behavioral sciences (e.g., Pagoto & Bennett, 2013) but are only recently moving into the information sciences and computer sciences fields, where system design still tends to be done at a "one size fits all" approach and customization is often seen as an extra effort and expense. Fortunately, that is beginning to change, and user experience will play a much larger role in future systems development.

Telehealth and Telemedicine

Telehealth and telemedicine have been defined as the electronic exchange of health information between one location and another to improve patients' health (Health IT.gov, 2017). The traditional uses of telemedicine have been to provide access to care for individuals living in rural areas where there are no providers, using two-way communications such as videoconferencing and consultations with specialists at different locations (IOM, 1996).

More recently, the term telehealth has come to include a variety of provider-to-provider and provider-to-patient technologies—not only for virtual clinical visits, but also to share information and provide training and administrative services at a distance. After decades of primarily providing clinical services to Medicare beneficiaries and Native Americans living in rural and frontier areas, with some safety net telehealth studies supported by the Health Resources and Services Administration (HRSA), telehealth is now becoming one of the fastest-growing sectors in health care (Edmunds et al., 2017; Tuckson, Edmunds, & Hodgkins, 2017).

Recent estimates from the Department of Health and Human Services indicate that more than 60% of all health care institutions currently provide at least some telehealth services (ASPE, 2016). Business sector projections indicate that by 2020, virtually all large employers will include telehealth services in health benefits packages (Freeman, 2016).

The Department of Veterans Affairs is greatly expanding its telehealth services, which already provide medical care to veterans around the country (Phillips & Fandos, 2017). Telehealth demonstration projects involving academic medical

centers and federally qualified health centers in urban areas are promoting access to specialty care and reducing patient travel burden through videoconferencing (Sikka, Redha, & Kirkpatrick, 2017). There are many other examples.

To meet urban and suburban consumers' increasing expectations of 24/7 access to clinical providers, companies like athenahealth, American Well, Avizia, Doctor on Demand, PM Pediatrics, Teladoc, and many others are developing new service lines and partnering with existing health systems to extend the availability of 24/7 services to more locations. To protect privacy and security while promoting continuity of care, for example, the UCLA health system negotiated a contract with CVS Health and MinuteClinic to allow connectivity to their employees' EHRs when they sought care remotely on evenings and weekends, when they could not see their usual clinicians (UCLA Newsroom, 2012).

In response to a Congressional request, the Agency for Healthcare Research and Quality (AHRQ) commissioned a technical review of the telehealth research literature (Totten et al., 2016) to help establish the strength of the evidence base for telehealth interventions. Based on hundreds of individual studies and dozens of systematic reviews, the review confirmed that telehealth generally improves access to care, reduces wait times, and increases patient satisfaction due to lower travel costs and time burden. Further, ongoing remote monitoring for patients with chronic conditions was shown to prevent unnecessary visits, to reduce unnecessary hospitalizations, and to provide additional clinical information that helps tailor treatments to individual needs (Totten et al., 2016). However, the strength of the evidence base varies for different chronic conditions (e.g., diabetes, cardiovascular disease, COPD). At this writing, a follow-on AHRQ-funded technical review is focusing on the use of telehealth for acute and chronic specialty consultations (AHRQ, 2017).

Some see telehealth as a natural extension and update of health care delivery processes to keep up with the larger culture and consumer technology adoption, but many payment and credentialing restrictions are still in place that prevent expansions (Center for Connected Health Policy, 2017). Recent legislation, including the Medicaid Access and CHIP Reauthorization Act (MACRA) and the 21st Century Cures Act, broadened coverage for telehealth for Medicare beneficiaries and initiated studies of its impact, which will be closely watched in the provider and policy communities in the coming years.

Self-Care, Patient Education, and Behavior Change

There was a time, not too long ago, when most health professionals were trained to believe that their patients were not capable of understanding complex medical information and had to be simply told what to do: lose weight, stop smoking, get more exercise. The main problem with that approach is that it doesn't work.

Even now, health professionals still receive relatively little training about how to help patients change their behaviors and lifestyle (Volpp, 2017). That may be one of the major reasons people have been turning to other sources of information, such as social media and online social networks, and why the digital health industry will

continue to attract entrepreneurs and start-ups who seek to increase consumer engagement in health through the use of new technologies.

Medical Self-Care, a pre-Internet print magazine, was an early pioneer in direct-to-consumer health communications. Tom Ferguson, a fourth-year-medical student at Yale, launched the magazine in 1976 as a "Consumer Reports focusing on health care" (Thomas, 1978), and then became influential in professional activities in consumer informatics. In addition to promoting the idea of social equity, in which providers and the people they treated had equal standing, Ferguson helped to formulate a framework of levels of engagement that moved from online searches for family and friends, to seeking guidance for their own conditions, to joining and making inquiries in online groups, and to communicating directly with clinicians through e-mail (Ferguson, 2002; Lewis, Eysenbach, Kukafka, Stavri, & Jimison, 2005). Future approaches to unifying the field might consider updating Ferguson's framework to take into account the dramatic changes in technology access and online literacy in the 15 years since he proposed it.

Another pioneer in personalized health information was Tom Pickering, an internist and hypertension expert at New York Hospital. Pickering specialized in behavioral medicine approaches that involved self-monitoring and identification of situations that would increase blood pressure at a time when it was still not generally accepted that individuals could intentionally decrease blood pressure through relaxation techniques and other behavior changes (Kabat-Zinn, 2003; Pickering, 1996).

After systematic studies with his team, Pickering coined the term "white coat hypertension" to refer to those individuals whose blood pressure was usually normal but was higher when they were seen in a clinic by a medical professional because they were "reactive" to being in the clinic (Pickering et al., 1988). These higher readings in the clinic could result in inaccurate diagnoses and unnecessary medications being prescribed, subjecting people to side effects such as dizziness and weakness. Ambulatory blood pressure monitoring was only in early stages at that time, but Pickering advised epidemiological research to compare the risk of heart disease over time for confirmed hypertensives and white-coat hypertensives (Pickering, 1996). Twenty years later, medical opinions are still divided on the matter.

One might wonder why it has taken so long for the work of Tom Ferguson, Tom Pickering, and other pioneers to influence the practice of medicine to incorporate more behavior change and health education. There are some professional organizations, such as the Institute for Healthcare Improvement, Society of Behavioral Medicine, the Society for General Internal Medicine, the Society for Medical Decision Making, the Society of Participatory Medicine, and others that emphasize the partnership of people with their providers in shared decision-making in improving health. Notably, the nursing profession has been writing about shared decision-making for more than 20 years (Charles, Gafni, & Whelan, 1999; Clark et al., 2009). But as Kevin Volpp put it recently, providers receive little training in "how to create an easily navigable health improvement pathway for the patient" (Volpp, 2017, p. 2).

The term "*patient-centered care*" was introduced by the Picker Institute in 1988 and was influential in the 2001 *Quality Chasm* report by the IOM. It was also a centerpiece of several provisions in the Affordable Care Act, reflecting the consensus about the need to improve quality through increasing patient engagement, and has been written about extensively (see, e.g., Berwick, 2009).

As it turns out, the adoption of "person-centered care," the practice now recommended by the NAM, is not an evolutionary step, but a revolutionary one. There are many sources of resistance to change (Berwick, 2009), and many consumer health groups have adopted the phrase "nothing about me without me" to more actively describe their ideal relationship with clinicians and care systems (Delbanco et al., 2001).

Digital Health: Tools of Empowerment

Digital health is an umbrella term used to describe the electronic information technologies and tools that deliver services to consumers and patients and help them manage personal health and wellness. New products and services are being developed all the time and can be classified in many ways.

Gibbons and Hoyt (2014) identify six basic categories of consumer health informatics tools. They are:

Mobile apps or consumer health applications designed for mobile devices such as smartphones and tablet computers. An estimated 165,000 health apps are available on the Apple Store, according to *The Guardian Science* (2017), a situation often described as the "wild west" because most are not based on the evidence of effectiveness or user input and often ignore existing technical standards.

Websites that are oriented toward health information have been developed by government, industry, health systems, and non-profit groups. Thousands have been launched, and some of the more successful are WebMD, mayoclinic.org, Medline Plus, Healthfinder, and Healthwise, a not-for-profit company with a patient education suite that can be adapted for different conditions.

Interactive health games can help teach about nutrition, healthy food choices, fitness, and other positive health behaviors.

Sensor-based tracking systems include devices that are wearable and/or embedded in clothing, as well as some that are implantable. They can track respiration rate, heart rate, blood pressure, breathing patterns, blood glucose, movement, and many other signs and symptoms.

Health-related social media include platforms like Facebook and Twitter, consumer and caregiver informational and support sites, business and industry rating sites such as Angie's List and Yelp, YouTube videos, and many others.

Virtual reality programs are mostly in the research and design stage but are showing promise with amputees, people with depression, and PTSD (Nichol, 2017).

These and other emerging digital technologies can be used for a variety of purposes, including searching for health information; exchanging health information with social networks and providers; tracking symptoms to self-manage chronic conditions; making appointments; requesting refills of prescriptions; recording and storing personal health data; updating and correcting medical data maintained by providers; consenting to participate in clinical trials and other research; and performing analytics on personal data to identify patterns and trends, among others

(Ahern, Kreslake, & Phalen, 2006; Center for Advancing Health, 2014; Gibbons & Hoyt, 2014; Pagoto & Bennett, 2013).

The global digital health industry is expected to reach over $200 billion by 2020, according to Statista (2017), driven largely by the mobile and wireless health markets. In the USA, digital companies are working on direct-to-consumer business models for online health information, online health reviews, mobile health tracking, wearables, consumer-driven genetic services, and telemedicine (Rock Health, 2015).

Contrary to the impression given by product advertising and marketing pitches, the majority of consumers are not yet using mobile apps. They are concerned about the privacy of their data, access to their own data, and actionability of their data, meaning whether their providers will view or use the data they gather on their Fitbit or other mobile monitoring device. Others download apps only to find them hard to use or lose interest because the feedback is not personalized or useful. There also are differences in adoption and use patterns for millennials and other "digital natives" who grew up in the digital age, compared with "digital immigrants" who acquired digital familiarity as adults and tend to view digital tools as add-ons.

Only about 20% of Americans are currently tracking a key health factor on a mobile app (Rock Health, 2015). However, close to 90% of people with online access to their health information will access it at least once a year and more than half log on three or more times a year (Mackay, 2015). A growing number of health systems have consumer portals for scheduling, prescription refills, health education materials, secure e-mailing with providers, and downloadable apps for fitness and nutrition tracking. These portals are not just about convenience, and they may prove to be the gateway to use of other technologies by a growing number of people if the technology is well designed.

It is well worth noting that the "digital divide" has been shifting recently. Between 2000 and 2010, the proportion of Black and Latino Internet users doubled (Smith, 2010) and nearly nine out of 10 Americans are now online (Smith, 2017). Racial and ethnic differences in access to desktop and laptop computers do not apply to mobile phones. Whites, Blacks, and Latinos now have similar rates of cell phone ownership, but Black and Latino people are more likely to use their mobile phones to access online health information compared to Whites (Anderson, 2015). Knowing about these access patterns is useful for planning preventive outreach strategies and designing treatment plans to manage chronic illness (National Research Council, 2016).

Population Health: Determinants of Health

Perhaps one of the greatest ironies of the US health care system—the most expensive system in the world—is that most of what determines health happens outside of the health care system (see Fig. 1.2). It is well established and understood that an individual's overall health is determined by a complex combination of personal, social, economic, and environmental factors. Among the personal determinants of health are biological and genetic factors (e.g., age, family history of cardiovascular

Fig. 1.2 The health equity conceptual model from the National Academy of Medicine Roundtable on Population Health Improvement shows the determinants of health with community-driven solutions that can address social, environmental, and financial inequities. Source: Culture of Health Tools and Resources, National Academy of Medicine (2016). Reprinted with permission from the National Academy of Sciences. Courtesy of the National Academies Press, Washington, DC

disease or cancer) as well as everyday personal health behaviors, particularly diet, physical activity, and smoking (McGinnis, 2013; McGinnis & Foege, 1994; Teutsch, 2015). Despite the Healthy People 2020 goals of "attaining the highest level of health for all people," evidence of racial and ethnic disparities continues to crosscut all of these behavioral, social, and environmental factors.

In 2010, nearly half (48%) of all early deaths were linked to personal health behaviors and other preventable causes such as poor diet, high blood pressure, obesity, and tobacco use (McGinnis, 2013). Smoking is still the leading preventable cause of death in the USA, killing almost half a million people every year (CDC, 2016) https://www.cdc.gov/tobacco/data_statistics/sgr/50th-anniversary/index.htm. A disproportionate number of those deaths are among African-American men (Ho & Elo, 2013).

Tobacco use has been the target of personal and policy interventions in the USA for more than 50 years. In 1964, an advisory group to Surgeon General Luther Terry submitted the first federal report that linked smoking with poor health, including lung cancer, heart disease, and low birth weight. Pressure from public health officials and consumers continued until 1970, when President Nixon signed legislation requiring warning labels that said "Cigarette Smoking May be Hazardous to Your Health" (History.com, n.d.). More recent public health efforts, such as those to reduce obesity by limiting access to sugary drinks, have met with significant opposition from the food and beverage industry and small businesses, among others, but have had some limited success in changing the purchasing patterns and food programs in school systems and making alternative, healthier beverages available (e.g., Freyer, 2016).

Although the fundamental purpose of government is to provide for the public good and act in the public interest, the federal government has no actual constitutional authority for health. States bear the legal responsibility for health, along with health insurance, professional licensure and credentialing of health care providers, emergency preparedness, and other vital functions. The lead federal public health agency, the Centers for Disease Control and Prevention (CDC), relies on cooperative agreements with states and voluntary frameworks, such as Healthy People 2020 or standards developed by professional organizations (Edmunds, 2014), to implement programs and collect health data, resulting in a patchwork of requirements and payment policies that have slowed the implementation of telehealth services, standardized professional credentialing, and expansion of other digital health interventions.

However, CDC and other members of the public health and medical communities have successfully partnered with federal agencies and private sector partners for decades to produce social marketing and public education campaigns designed to promote awareness and help to change behavior (e.g., see Fig. 1.3). The classic resource on social marketing in health was produced by the National Cancer Institute and released in 1989. *Making Health Communication Programs Work* (also known as the "pink book") is still one of the most valuable resources for health communications campaigns (NCI, 1989).

Topics of CDC's recent social marketing and educational campaigns include HIV prevention, smoking, dental health, bone health and osteoporosis, preventing falls in seniors, chronic fatigue syndrome, pre-diabetes awareness, and many others that are evidence-based, tested with a variety of ages and racial/ethnic groups, and free to the public.

The best campaigns are based on formative marketing research with diverse target audiences, looking for gender, racial, ethnic, cultural, and other differences; systematic message development, testing, and refinement to be scientifically accurate but understandable; strategic choices of media channels (e.g., texting, Facebook, or personal outreach); and evaluations of effectiveness. Studies have consistently shown that many behaviors are not easily changed; that multiple attempts and strategies are usually required; and that information and communication technologies can help in myriad ways to advance health promotion and disease prevention (Pagoto & Bennett, 2013; Teutsch, 2015).

Fig. 1.3 In January 2016, the first-ever national campaign on pre-diabetes awareness was launched on 33,000 TV, radio, print, and digital media, with the goal of making it funny so people would pay attention. Source: Developed by the American Diabetes Association, the American Medical Association, the Centers for Disease Control and Prevention, and the Ad Council. Used with permission (https://www.cdc.gov/features/prediabetes-awareness-campaign/index.html)

Community Engagement

In addition to publicly funded activities to promote population health, several philanthropic foundations have funded community health promotion activities, including the Annie E. Casey Foundation, the W. K. Kellogg Foundation, the Kresge Foundation, The Robert Wood Johnson Foundation, and many others. Community-based coalitions have addressed the social and environmental determinants of health—such as access to clean water, safe areas for recreation, exposure to environmental toxins—through awareness campaigns, door-to-door outreach, local regulations and legislation, and direct action, such as when public officials' negligence and implicit racial bias led to the Flint, Michigan water crisis (Kennedy, 2016).

Multi-sector community partnerships all over the country are working on a wide variety of issues that affect social, economic, and environmental determinants of health, sometimes with external or local funding and sometimes purely on a voluntary basis. The healthy cities and communities movement, which started in Europe

with support from the World Health Organization, has been operating in the USA for more than 25 years. The movement's many success stories and case studies show the variety of ways engaged citizens can help produce healthier environments and have been well summarized by Mary Pittman of the Public Health Institute (Pittman, 2010). It's worth noting that social media, such as Facebook pages and neighborhood listservs, are rarely mentioned but frequently act as the catalysts that help to organize and promote engagement to improve community health.

International Ratings and Rankings

If health care spending produced health, the US population would be among the healthiest in the world. Paradoxically, however, the USA spends more on health care than any other country and still has shorter life expectancy and poorer health than most other OECD countries (Bradley, Elkins, Herrin, & Elbel, 2011) as well as extensive racial/ethnic and income disparities.

After extensive studies of social and health spending in the OECD countries (Organization for Economic Cooperation and Development), Bradley and her colleagues have found definitively that spending on social care, such as nutrition, child care, transportation programs, and other social supports, helps to keep people healthier and reduces their need for medical care (Bradley & Taylor, 2015).

It's not hard to see that a program like Meals on Wheels, for example, can benefit isolated older people both socially and nutritionally. By choosing to separate medical, social care, and community support systems, the USA ends up spending more for medical care with less beneficial results, totally apart from the higher costs of medical technology and prescription drugs.

As more baby boomers choose to stay in their homes and "age in place," there will be many more opportunities for them to use online contacts through remote monitoring, texted medication reminders, virtual visits with care teams, and other consumer-friendly technologies to keep them connected with family and community members, providers, and others. According to Aging in Place Technology Watch and other industry observers, the digital health industry sees many opportunities in the aging population. Similarly, the Personal Connected Health Alliance has developed and promotes the use of design guidelines to help ensure that technology is integrated into people's everyday lives.

Emerging Trends and Future Opportunities: What Do People Want?

Creative use of mobile devices, wearables, and other digital tools has the potential to improve quality of life and promote well-being while reducing health care burdens and costs, but only if done in a thoughtful, personalized, and respectful way.

Nine out of ten adults in the USA say that they want to engage in shared decision-making (HIMSS, 2014), but that requires changes in organizational cultures to promote a "fabric of trust," in which all parties participate as equal partners (Grossman, Powers, & McGinnis, 2011).

Trust is built when there is confidence that personal information will be shared in accordance with personal preferences, and that the information will be secure, available when needed for shared decision-making, and not subject to breaches (Mackay, 2015; Petersen, 2016). At this point, the best we might say is that shared decision-making is a "work in progress" (Berwick, 2009; Rock Health, 2015; Tan & Goonawardene, 2017).

Access to personal health data is a significant motivator for many activated people who are living with chronic medical conditions themselves, or caring for a family member or friend with a chronic condition (Mackay, 2015; Petersen, 2016; Standen, 2012). Hugo Campos, who has genetic heart disease, actively sought access to the data produced by his implanted medical device manufactured by Medtronic (Parmar, 2013). Megan O'Boyle, whose daughter has a rare genetic disease, became active in developing a registry of parent-reported information despite her initial resistance about research (PCORI, n.d.). Carolyn Petersen, a patient and consumer advocate, notes that wearables, sensors, and other digital applications expand the opportunities for patients to collect more personal health information, but cautions that reuse of their data for clinical research and other purposes will require new processes for managing the data. In addition to improvements in consent, these include "greater security, transparency, and appreciation of patient contribution and perspectives" (Petersen, 2016).

Better tools are essential for future engagement strategies. In addition to the out-of-pocket costs of purchasing and maintenance, consumers view poor design and limited usability as technology deal-breakers (Brennan et al., 2015a; Center for Advancing Health, 2014; Dixon-Fyle, Gandhi, Pellathy, & Spatharou, 2012; and Volpp & Mohta, 2016). Perhaps we could apply some of the lessons learned from the national adoption of electronic health records (EHRs) under HITECH, in which many clinicians were viewed as being anti-technology when many were reacting to software design flaws, limited training, and impacts on workflow.

We have much more to learn about people's preferences for technology use, taking into account personal differences in age, gender, race/ethnicity, cultural background, and health beliefs. According to one consumer survey, people who need to manage a personal health condition, either their own or someone else's, are more likely to overcome their resistance to poor technology design and other obstacles in order to control their own health data if they think it will improve their health (Rock Health, 2015). They will also share the data readily if they think it will help others and trust those with whom they are sharing.

Summary and Conclusions

According to a McKinsey report (Dixon-Fyle et al., 2012), nearly one-third of the $3 trillion in annual US health care costs can be attributed to chronic conditions that can be influenced by personal behaviors. Behavior change is hard, but not impossible. There is ample existing evidence about the effectiveness of multi-component change management strategies for health behaviors, but the evidence is scattered throughout dozens of professional journals and research organizations and tends to be concentrated by disease or medical condition, such as cancer, diabetes, asthma, heart disease, and osteoporosis.

Still, we know that the same core health behaviors (e.g., smoking, overweight, sedentary lifestyle, and poor diet) are risk factors for multiple diseases, and we know how to help people change those behaviors to reduce their risk. Because of social and environmental determinants associated with where people live, work, and play, additional changes and supports may be needed beyond just what an individual and family can manage. At the health system level, human-centered design principles can be used to create a better experience for everyone (O'Connor, 2017). At the neighborhood level, community health and social connections can be promoted by turning an abandoned lot into a community garden with its own Facebook page.

All over the country, innovative ways to link community health with clinical health are emerging because of new value-based payment initiatives and projects initiated under the Affordable Care Act and philanthropic investments. Multidisciplinary care teams are working with community leaders to address the social and environmental determinants of health, whether through adapting health and social care models or finding other ways to bring people and systems together. We think it's the right time to let digital strategies and tools help show what a "high tech high touch" approach can do for health.

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Chapter 2
Introduction to Consumer Health Informatics and Digital Inclusion

M. Christopher Gibbons and Yahya Shaikh

Introduction and Overview

In 1999, less than two decades ago and a mere 5 years after Netscape publicly released its first web browser, marketing executives coined the term *e-Health* to convey the promise and potential of the application of e-commerce to the health sector. The term represented not only a technical vision, but perhaps more importantly, a philosophical view and excited commitment to the development of a globally networked world that could capitalize on the potential of Information and Communications Technologies (ICT) to improve health (Eysenbach, 2001).

This vision was based in large part on the potentially transformational power of the Internet and the belief that associated networked electronic technologies would offer new and unprecedented opportunities for healthcare to (1) enable consumers to interact directly with the healthcare system; (2) enable improved institution-to-institution transmissions of data; and (3) catalyze new possibilities for engagement with and among patients, caregivers, and consumers (Frank, 2000).

Just one year later, in 2000, Seth Frank introduced the term *digital health* to refer specifically to the use of interactive media, tools, platforms, applications ("apps"), and solutions that are connected to the Internet to address health concerns of providers as well as consumers (Frank, 2000). Frank believed that the Internet and digital tools offered consumers the ability to more effectively access information, enhance informed and shared decision-making, enable health-promoting social interactivity, support self-care, lessen demand for healthcare services, and lower direct costs to consumers. He also believed that combining the Internet with other interactive technologies (e.g., voice recognition systems) could help reduce the need for or use of unnecessary medical services (Frank, 2000).

M. C. Gibbons (✉) · Y. Shaikh
Johns Hopkins University School of Medicine and The Greystone Group, Inc., Washington, DC, USA
e-mail: mcg@greystonehit.com

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The term *consumer health informatics* emerged in 2001 to explicitly distinguish the needs and perspectives of consumers, patients, and caregivers using emerging electronic tools from those of healthcare providers as "medical tools" were being developed (Gibbons et al., 2009). Today, consumer health informatics solutions are defined as "any electronic tool, technology, or electronic application that is designed to interact directly with consumers, with or without the presence of a healthcare professional, that provides or uses individualized (personal) information and provides the consumer with individualized assistance to help the patient better manage their health or health care" (Gibbons et al., 2009).

From this brief description of the history of the consumer health informatics sector, it is clear that there are many types of consumer informatics tools that can be or are being used for health purposes. Many of these technologies have been reviewed elsewhere (see Gibbons, 2011; Gibbons & Hoyt, 2014), and some of the specific categories include electronic health records (Marchibroda, 2014); patient portals (Irizarry et al., 2015); mobile health, i.e., smartphones and wearable devices with wireless connections; telehealth and telemedicine (e.g., Assistant Secretary for Planning and Evaluation, 2016; Edmunds, Tuckson, Lewis, et al., 2017); and social media (Smailhodzic, Hooijsma, Bonstra, & Langley, 2016).

It is beyond the scope of this chapter or this book to provide an exhaustive discussion of every technology. Rather, the chapter seeks to focus on the technology types, examples, and perspectives that have received comparatively little previous discussion yet are incredibly important, either because (1) they are known or believed to be able to significantly impact the health of consumers; or (2) because they are already being used by the majority of consumers and therefore offer potential for being able to reach everyone for health purposes.

The chapter begins by briefly outlining the major societal trends and forces that have helped to catalyze the emergence of consumer health informatics. We then shift to a brief discussion about the key components of consumer health informatics systems. Next, the chapter will move to a discussion of the future evolution of consumer health informatics solutions. Finally, the chapter will close with a brief discussion of major challenges and barriers to the continued growth of the consumer health informatics sector, followed by a brief chapter summary and conclusions.

National Trends Causing the Emergence of Consumer Health Informatics

Infrastructure Trends

Ubiquitous Broadband

Networks have a transformative effect on society (Federal Communications Commission, 2010). Consider the following US examples.

In the 1860s, transcontinental railroad networks did more than transport people: They also brought cattle from Cheyenne to the stockyards of Chicago, catalyzing commerce in the food industry.

In the 1930s, electricity networks enabled significant improvements in agriculture and brought industry to the Smoky Mountains of Tennessee and the Great Plains of Nebraska, which sparked major advances in the farming sector.

In the 1920s, 1930s, 1940s, and 1950s, telephone networks, and radio and television networks all transformed America, which unleashed new opportunities for American innovators to create products and industries, new ways for citizens to engage their elected officials, and a new foundation for job growth and international competitiveness.

In the 1950s, the Interstate highway network fueled jobs on the manufacturing production lines in Detroit and in the shipping warehouses in Los Angeles (FCC, 2010).

Today, broadband Internet is transforming the US landscape more rapidly and more pervasively than earlier infrastructure networks. Like railroads and highways, broadband accelerates the velocity of commerce and reduces the impact and costs of distance. Like electricity, it creates a platform for innovation. Like telephones, radio, and television, it expands our ability to communicate, inform, and engage.

Ubiquitous access to infrastructure networks has continually driven American innovation, progress, prosperity, and global leadership. (FCC, 2010). Despite this reality, it is important to remember that the network alone is not transformative: rather, it is the ecosystem of the networks and associated tools, devices, and platforms that enable the transformations. In other words, it is what the network enables that is transformative (FCC, 2010).

This has been true in every sector that has embraced broadband networks and ecosystems. We are beginning to witness similar disruptive and transformative changes in health care. If what happened in other sectors is illustrative, then the widespread availability of affordable broadband will cause the healthcare systems of the future to look radically different than they do today for both providers and consumers.

Growth of Consumer Electronic Technology Utilization

According to the latest figures from the Pew Research Center, as of 2016, 95% of US adults own a cell phone and 3 out of 4 (77%) are smartphone owners (Fox & Duggan, 2012). In addition, 31% of cell phone owners use their phone to look for health or medical information online.

Younger adults, minorities, and those in particular need of health information are most likely to use their phones to obtain health information (Fox & Duggan, 2012). African Americans are twice as likely as Whites to use their phones as the primary method of getting online (38% vs. 17%), and they are more likely to own a mobile device and use a wider array of functions on these devices than whites (Zickuhr & Smith, 2012). Finally, there is mixed evidence regarding the use of social media by

race. Some reports suggest significantly higher utilization of social media by minorities, and other reports suggest uniformly high rates of social media across racial subgroups (Gibbons et al., 2011; Korzenny & Vann, 2009).

There is another technology that is even more ubiquitous than the cell phone. The television has come a long way since the days of rabbit-ear antennae and analogue TV sets. Today the newest televisions are smart, connected, and interactive. As of 2012, 97.1% (114,700 of 118,590) of US households had at least one television (Television Bureau of Advertising, Inc., n.d.). Given this reality, cell phones, personal computers, and DVD players are currently found in over 80% of total US households.

This is important because the number of US mobile subscribers watching video (TV shows/movies) on their mobile devices has risen over 40% in recent years. These individuals are spending a lot of time each day viewing TV content. A recent study found that 13–17 year olds spent approximately 7–9 h viewing a day, adults spent approximately 3–7 h/day viewing, while seniors over the age of 50 spent approximately 2–3 h/day viewing TV content *on their mobile devices*. By 2009, the average TV household was spending almost 8.5 h watching the television each day with women spending on average over 5 h, men about 4.5 h, and children about 3.5 h each day (TBA, Inc., n.d.).

To put this in perspective, US adults spend more time with television than with newspapers, radio, magazines, the Internet, and mobile devices *combined*. This enables digital content to reach almost 90% of adults over the age of 18 (TBA, Inc., n.d.). Finally, because of TV's reach, significantly more people learn about products and services that they would like to purchase from TV (39.8%) than any other source (less than 10% for any other source including radio, Internet, and mobile devices) (TBA, Inc., n.d.).

Interestingly though, some evidence suggests that the Internet has considerably more influence over actual consumer health decisions and behaviors than traditional channels like print, radio, and even TV (Manhattan Research, 2010). For these reasons, any discussion about the role of technology in health must include a discussion about all consumer technologies which could be effective channels to reach, engage, and interact with patients, consumers, and caregivers.

Demographic Trends

US Population Surge

In 1950, there were 152 million Americans living in the USA. The number of individuals living in the USA and therefore potentially needing health services is rising rapidly, and today there are over 320 million people. This represents an increase of approximately 168 million people (110%) in just 67 years. Furthermore, the number of people living in the USA is projected to be 400–450 million people by 2050 (Shrestha & Heisler, 2011).

This rate of growth easily surpasses other industrialized countries such as Germany and Italy, which have generally grown by rates between 20% and 30% during the same time period. Several other countries, particularly in Eastern Europe, have actually had reductions in the size of their populations (Shrestha & Heisler, 2011).

Aging of the US Population

In addition to an increase in the numbers of people living in the USA, the population is getting older, with large increases in the total number of seniors and the proportion of seniors relative to the total population. In 1950, the 152 million consumers living in the USA had a median age of 30.2 years, and children under the age of five accounted for 10.8% of the total population. However, by the US 2010 census, the median age had increased to 37.2 years, and the proportion under the age of five had dropped to 6.5% of the total population (Howden & Meyer, 2012).

By way of contrast, in 1950, the senior population represented 8.1% of the total population. Yet by 2050, it is projected to reach 20.2% of the population. By then, fully 20% of people (88 million people) will be 65 or older and another 32.5 million (7.5% of population) will be over the age of 80 (Shrestha & Heisler, 2011).

Increasing Prevalence of Chronic Diseases

In addition to grappling with a population surge and increasing longevity, growing evidence points to an increasing national prevalence of chronic diseases, which in some cases has been described as being of epidemic proportion. National statistics indicate that chronic diseases in the USA are the leading cause of sickness, hospitalization, and death (Bauer, Briss, Goodman, & Bowman, 2014). More than 50.9% of US adults have at least one chronic disease, while 26% of all adults and approximately 50% of seniors will have at least two during their lifetime (Ward & Schiller, 2013).

At least seven of the top 10 causes of death in the USA are chronic conditions, including heart disease, cancer, chronic lung diseases, stroke, Alzheimer disease, diabetes, and kidney diseases. People living with chronic diseases use significantly more health care services and other health resources than those without chronic diseases. As a result, chronic conditions result in significant costs and human burdens on patients, families, employers, and health systems (Bauer et al., 2014).

Growth in Population Diversity

In addition to an increase in numbers, the US Census Bureau data indicate increasing racial and ethnic diversity of the US population. "Minorities" currently account for approximately 37% of the population and will rise to approximately 57% by 2060 (U.S. Census Bureau, 2012).

Non-Hispanic whites are projected to increase slightly until 2024, then will decrease, falling by nearly 20.6 million by 2060. The Hispanic population will more than double to 128.8 million by 2060 representing fully one-third of the US population. The Asian population is expected to rise to 34.4 million or 8.2% of the population while African Americans will increase to 61.8 million or 14.7% of the population by 2060. Finally, the numbers of American Indian and Alaska Natives and Hawaiian and Other Pacific Islanders will rise but only account for approximately 1.5% of the total population in the next 40 years (U.S. Census Bureau, 2012).

These changes in the numbers of racial and ethnic minorities will mean that the total minority population in the USA will more than double over the next 40 years. Seniors will be largely non-Hispanic white, while younger individuals will more likely be a racial/ethnic minority, and the USA will become a majority–minority nation by 2043. Non-Hispanic whites will still be the largest single racial group, but no group will form a majority (>50%) of the total population (U.S. Census Bureau, 2012).

Healthcare Sector Trends

Finally, to complicate matters further, the healthcare system itself is struggling with additional forces impacting the ability to meet patient, family, and consumer needs. Briefly, these include the following:

Healthcare Workforce Shortages There is a growing concern about increasing workforce shortages in the US healthcare system. This is happening for several reasons. First, physician demand is outstripping supply, with a shortfall of between 46,100, and 90,400 primary care and specialty physicians projected to occur by 2025 (Dall, West, Chakrabarti, & Iacobucci, 2015). The shortfall is expected, however, to be most significant among surgical specialties. The impact of these combined shortfalls will be felt most acutely by underserved consumers in rural and inner city areas (AAMC, 2010).

For the nursing workforce, projections suggest a shortage of as many as 400,000–808,000 nurses by 2020. The current workforce is aging and increasing numbers of nurses will be retiring (Buerhaus, 2008).

Rising Healthcare Costs Another important trend impacting health care is the rising costs of care delivery. It is well known that US healthcare costs have risen, largely unabated, for more than 20 years. In 2015, the US National Health Expenditure

grew 5.8% to $3.2 trillion in 2015, or $9990 per person, and accounted for 17.8% of Gross Domestic Product (GDP). Soon, national health expenditures will consume more than 20 percent of the GDP. Health spending is projected to grow 1.2 percentage points faster than Gross Domestic Product (GDP) per year over the 2016–2025 period; as a result, the health share of GDP is expected to rise from 17.8 percent in 2015 to 19.9 percent by 2025 (CMS, 2017).

Healthcare Delivery and Financing Changes In part due to the rising costs of US health care in the USA, healthcare practices and associated medical devices and information technologies are rapidly moving beyond the walls of the hospital and into people's homes (National Research Council, 2011). In fact, lengths of stay at US hospitals have actually been decreasing for more than 50 years. In the past, patients could remain in the hospital for full diagnostic work-ups, treatment, and recovery; however, today, there is much more focus on stabilizing the patient, minimizing the duration of hospitalization, and accomplishing the diagnosis, treatment, and recovery in the outpatient setting as much as possible. The major causes for these changes, especially in the last two decades, include the growing use of technology in health care and increasing financial pressures on hospitals (Kalra, Fisher, & Axelrod, 2010).

Even as technology may be playing a role in driving up the costs of care, there is much excitement regarding the use of new technologies to improve clinical care processes, clinical decision-making, and health outcomes. Given its focus on consumer health informatics, this chapter will only provide a high-level overview of these technologies.

The types of technologies being used in the clinical delivery of health care span a wide spectrum. Much of the early focus has been on the potential of Electronic Health Record Systems (EHRs) and other forms of health Information technologies (Health IT). Today, the clear majority of physicians, nurses, and hospitals use EHRs on a daily basis (ONC, 2017).

In addition, the use of telemedicine and telehealth platforms is becoming more popular among providers (Tuckson, Edmunds, & Hodgkins, 2017). Another technology gaining widespread use, particularly among surgeons and other specialist physicians, is the use of robotics to perform direct actions on a patient at a distance (e.g., Weissman & Zinner, 2013). Also, a variety of sensor technologies are now emerging as important clinical aids that enable providers to monitor a potentially unlimited number of patient, or environmental factors in real time, anytime, anywhere (see Chap. 18).

Healthcare Disparities A large and growing body of evidence demonstrates that racial and ethnic minorities tend to have poorer health status, poorer access to health care, lower adoption of health-promoting behaviors, and are less likely to live in healthy environments. For example, African Americans are 50% more likely to die early of heart disease or stroke (i.e., before age 75 years) than Whites (Gillespie, Wigington, & Hong, 2013). Diabetes rates are higher among Hispanics and African Americans than among Asians and non-Hispanic whites (Beckles & Chou, 2013).

The rate of infant mortality among African Americans is double that of whites (MacDorman & Mathews, 2013).

For over a decade, the Agency for Healthcare Research and Quality (AHRQ) has tracked more than 200 healthcare process, outcome, and access measures, covering a wide variety of conditions and settings (AHRQ, 2016). AHRQ consistently finds that healthcare disparities are common across minority groups. They also find that measures of disparities may change unevenly and inconsistently from year to year, but over time, few significant and sustained improvements have been made in any reported health or healthcare gaps (AHRQ, 2016).

Disparities persist for a variety of sociocultural, socioeconomic, behavioral, environmental, and healthcare system factors that exist within the context of current and historical biases and prejudices found in the healthcare system and society as a whole (IOM, 2003). In addition, significant levels of mistrust and challenges in cross-cultural communication exist among many racial and ethnic minorities and healthcare providers (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007; LaVeist, Isaac, & Williams, 2009; LaVeist, Nickerson, & Bowie, 2000).

Cumulatively, these demographic trends exert significant impacts on the traditional healthcare system that tend to render it unable to communicate, engage, or at times even understand the needs and perspectives of the patients it seeks to serve. In addition, these factors tend to create frustration, mistrust, and disillusionment among some members of the population when the system is unresponsive or poorly responsive to their needs and concerns. As such, given the infrastructure trends outlined above, consumers are increasingly turning to technology-based solutions to obtain the health supports and address the health concerns the traditional system is unable to handle satisfactorily.

Key Components of Consumer Health Informatics Solutions

Rapid advances in computing technology and the widespread availability of broadband networks are catapulting computing into an age in which computer systems can increasingly be thought of in terms similar to the human central nervous system (CNS).

Briefly, the human CNS consists of sensory (afferent) nerves that enable us to hear, feel, taste, and smell. These "sensory" nerves carry information about the things we sense, to the brain. We also have "motor" (efferent) nerves that carry information from the brain to the muscles in our hands, arms, legs, and feet about what to do in response to the things we have sensed (e.g., run, smile, move our hand, etc.).

The brain, then, is the control center that both interprets information about what is sensed and provides information about what to do about it to special cells called effectors (an organ or cell that acts in response to a stimulus). In both cases, the information is carried by a network of nerves that are connected to the brain and either "sensors" or "effectors."

In a real sense, then, although the brain is critical, it is the entire network consisting of the brain, afferent and efferent neurons (nerves), and sensory and effector cells, as well as the information that is conveyed on the system, that enable the coordinated and complex thoughts and actions of which life is made.

In the same way, although infrastructure networks are transformational in society (electricity, phone, etc.), it is the ecosystem of networks, applications, devices, and individual actions that drives value in reality, not just the network itself. Thinking of consumer health informatics systems from this more functional perspective may help us maximize the potential of these systems. This is because, by applying this perspective to consumer health informatics, we can develop more robust insights and understanding of the critical functions and necessary operational components that will drive value in the field without having to try to detail an ever-expanding list of applications and devices, tools, and technologies that are currently being used or will be used, in the future. This type of thinking can also facilitate early recognition and appreciation for potential future opportunities and applications of consumer health informatics.

Employing this perspective to consumer health informatics, then, we can understand the afferent arm of the field to include any type of hardware or software platform, device, app, or technology that enables us to "sense" or capture any type of data (e.g., visual, audio, text, vital signs, environmental, etc.) about an individual, place, or population, whether in real-time, synchronous, asynchronous, "on demand," or otherwise. Specific afferent or sensory tools would include wearables, home/automobile-based sensors, smartphones, online support groups, computers, video monitors, digital cameras, etc.

On the other hand, the efferent or interventional arm of the field includes any platform, device, app, or technology that responds to or otherwise performs an action in response to specific information or data about a given person or population, whether in real time, "on demand," or not. This could include simple functions like sending a consumer or provider an alert, or more complex computational actions like hearing a verbal question asked by a consumer about the proper way to change a surgical operative dressing and instantly receiving verbal or video-based instructions on how to perform the task properly. Obviously, then, many consumer health informatics tools have both afferent and efferent capabilities that enable a wide range of simple and complex actions.

In order to accomplish these tasks, however, the devices themselves must be connected to the "brains" of the system. In the past, the brains were always a human (e.g., doctor, nurse, etc.), and these systems would therefore be considered medical or clinical systems. Increasingly, however, the brains of these consumer health informatics systems are consumers or other computer systems themselves, often located at remote sites ("the cloud") from where the data is being collected, the actions are being taken, or insights are being delivered. These "control" computers use sophisticated programming languages, algorithms, and operations to detect, interpret, and control the sensing and interventional functions they control for consumers (see Table 2.1 for the authors' brief definitions of key terms).

Table 2.1 Key CHI infrastructure concepts

• *Cognitive Computing*—Type of computing that learns through experience, like the human brain
• *Neural Networks*—A system of hardware and/or software patterned after the operation of neurons in the human brain
• *Deep Learning*—Deep learning refers to artificial neural networks that are composed of many layers similar to how nerves are arranged in the human brain
• *Artificial Intelligence (AI)*—The ability of computer systems to imitate intelligent human behavior
• *Data Mining*—Computer processes which enable the analysis of very large data sets to identify patterns and meaning
• *Internet of Things* (IoT)—The system of machines and devices connected by broadband networks that do not require human intervention to transfer data and complete tasks
• *Edge Computing*—Networked computer processing that occurs at the site data collection on the network instead of relying on a single centralized processing network configuration
• *Cloud Computing*—The practice of using remote, Internet-based servers instead of local servers on a personal hard drive to store, process, and manage information

Finally, these computer-based tools, devices, and systems are connected by wireless or wired broadband Internet networks, which enable the bidirectional transfer of data and information. Because the networks can enable a potentially infinite number of connections between afferent and efferent consumer platforms, devices, apps, or other technologies, the broadband network and connected technologies have been referred to as an emerging *Internet of Things*. Also, as computing power continues to increase to the point where hundreds of thousands, and at times, millions of operations can be performed by computer chips that themselves are continually getting smaller, it enables simple and complex sensing, computational, data transfer, and interventional tasks to be performed in an instant, at any time day or night, for the benefit of any consumer connected to the network.

The Future of Consumer Health Informatics

While the emergence of new consumer health informatics tools, platforms, devices, and apps is exciting and may ultimately help improve consumer health, a device- or app-driven vision of the field is also limited. How many consumer health apps can anyone use effectively at the same time? How many different wearable devices will consumers be willing or able to wear and interact with each day? As the numbers of devices proliferate, what impact will it have on our interactions with the people and the world round us? If more and more of our time is focused on a screen, display, or dashboard, there will inevitably be less time to interact with the people and environments in which we live.

The most powerful technologies are those that weave themselves into the fabric of everyday life until they are indistinguishable from it and disappear (Weiser,

1991). Current consumer health technologies cannot truly make computing a seamless, invisible part of the way people live their lives precisely because they demand our active engagement, consent, and utilization. If these tools continue to demand engagement, at some point, we will reach our individual and collective limits in terms of the number of tools we can efficiently and effectively use at any one time.

The future of consumer health informatics will inevitably need to be based on designing tools that are, in fact, passive. In other words, they are invisible, operate automatically in the background, and do not require the user to do anything.

To illustrate, consider the fact that at the turn of the century, a typical workshop or factory contained a single engine that drove dozens or hundreds of different machines through a system of shafts and pulleys. The introduction of electrical networks enabled the production of cheap, small, efficient electric motors. These, in turn, opened up the opportunity to give each machine or tool its own source of power. This ultimately led to the ability to put many motors into a single machine.

As a result, for example, today's typical automobiles have at least two dozen or so "motors" that do everything from starting the engine and wiping the windshield to locking and unlocking the doors, etc. Although it may be theoretically possible to know when each of the motors is activated, there is really no point to doing so (Weiser, 1991). They have become invisible, working in the background automatically, with minimal-to-no active consideration by the driver. Indeed, for many drivers, it is inconceivable to think of owning a car in which there are no windshield wipers, power door locks, or where there is a need to physically crank the engine to start the car.

Similarly, future consumer health informatics tools stand to be considerably enhanced if designed less as stand-alone solutions and more as ecosystems of connected consumer technologies that optimize consumer health supports. In Boxes 2.1 and 2.2, we provide two examples of future consumer health informatics tools that are developed from this connected ecosystem perspective.

Box 2.1 Healthy Homes that Keep You Healthy

Suzie is a 6-year-old girl who has asthma requiring the use of a rescue inhaler approximately once per week. Suzie and her parents recently moved into a new smart care community that was advertised as being optimized for health. A major selling point of the new home was the multiple sensors and health technologies that were built into the home in ways that kept them unseen and working automatically without the need for Suzie or her parents to press a button or otherwise choose to use them. The sensors can detect any number of issues, concerns, and health conditions. Over time, the home will also "learn" the habits and behaviors of family members. When an issue arises, the home will determine what is occurring and correctly initiate a course of action that will appropriately address the issue.

Box 2.1 (continued)

One night, after bedtime, Suzie begins to have to work harder to breathe. Before she wakes up, the smart home recognizes that it is an early sign of an impending asthma attack. Suzie's parents are asleep in the next room and unaware of her changing condition. Before Suzie fully wakes up, the smart home has raised the humidity level in her room and released an appropriate amount of Susie's nebulized medication, into her room through the heating vents in her room. Suzie begins to breathe the warm, moist, medicated air and her asthma attack is prevented without any human intervention; her parents are unaware of the potential incident until they receive a home alert delivered to their mobile phones detailing what happened. Suzie's parents quickly run to her room and find her sleeping soundly in her bed.

Box 2.2 Dinner Time Technology

Joan is a 57-year-old, divorced mother of three teenagers who is also diabetic. Joan works as a sales clerk at a local department store and struggles to provide healthy home cooked meals for herself and her children while working full time and keeping up with all their after-school activities. On most days, she drops her children off at school by 7:30 am and travels to the store where she works weekdays from 8 am to 6 pm. She then rushes to pick up her children who are often at three different after school activities, to get home by 7:30 pm. After a long day, at that time of night she is in no mood to spend another hour cooking. In the past, it was a constant battle between eating well but late of eating earlier and eating out. Recently however, the community association made some upgrades to her apartment and home appliances. Now whenever she wants she simply tells Ida what she has a taste for, and in an instant, Ida tells her what she can make in 15 min or less, and which agrees with the diabetic diet her doctor prescribed, with what she already has in her cupboards.

In the first example, motion, respiration, and sleep quality sensors deployed in the bedroom detect breathing problems as soon as they begin, and within a fraction of a second, the data is transmitted to a cloud repository where it is combined with data from Suzie's personal health record, medication history, and pediatrician-visit and school-attendance records to determine a history of asthma treated with an inhaler, or nebulizer treatments of humidified air and nebulized medication. Given the current symptoms and associated data, the house correctly determines that Suzie is having an impending asthma attack, and before she completely wakes up, automatically gives her an equivalent dose of medication as that of her inhaler. Prior to notifying Suzie's parents, the home verifies that her breathing and sleeping patterns have returned to normal, and the full asthma attack has been prevented.

In the second example, Joan relies on Ida, an interactive, voice response-enabled, dietary-assistant avatar built into the display on her smart stove. Ida recognizes voice commands and uses radio-frequency identification and private and proprietary nutritional databases to identify the contents, date of purchase, nutritional content, and the quantity of unused items in her refrigerator and kitchen cupboards. Once done, the system compared available ingredients with millions of online recipes and found one that would fit into her diabetic diet plan that she could easily and quickly make with what she already had available.

Although still in the future, companies are actively exploring ways to bring both of these concepts to market. In a simple yet powerful way these examples illustrate the future potential of consumer health informatics that relies on broadband networks and connectivity to create an ecosystem of connected health supports to optimize patient health in a way that fades into the fabric of the lives of the consumer. These consumer health informatics solutions of the future work without imposing additional user tasks or relying on a certain level of consumer computer or health literacy in order for the system to work appropriately.

Consumer Health Informatics Challenges

As we have outlined above, current and emerging consumer health technologies offer significant promise in helping to improve health. Despite this potential, several substantial challenges remain that must be overcome to realize the full potential of consumer health informatics tools. We will briefly outline a few of the most pressing challenges below.

First, although broadband networks and broadband adoption is widespread, it is not universal. Estimates are that approximately 13% of the US population remain digitally unconnected (Anderson & Perrin, 2018). As a result, this percentage of the population is wholly unable to take advantage of the transformational possibilities consumer health informatics has to offer.

Perhaps more importantly, factors related to the design of the tools can significantly impact their utilization, and therefore, impact the likelihood of the user experiencing health benefits (Kaplan, 2004; Mansfield, 1987). For example, although technology designers often believe their creations to be culturally neutral, technology-based health tools are often embedded with "hidden cultural assumptions" that may not always be appropriate for all intended users (Valdez, Gibbons, Siegel, Kukafka, & Brennan, 2012). Furthermore, when this occurs across an entire population of users, the benefits may only be realized by some users, and therefore, culturally insensitive technologies can create or exacerbate health gaps between consumer populations (Valdez et al., 2012).

The privacy and security of data obtained and transmitted in consumer health informatics ecosystems has been repeatedly shown to be insecure, and the systems easily breached (Lin Goh, 2015). Despite this reality, given the strong consumer demand for emerging health technologies, it is unclear to what extent this reality is

impacting consumer attitudes or behaviors concerning consumer health informatics solutions. A detailed discussion about these issues is beyond the scope of this chapter, and this is an area that needs additional research.

Some literature suggests that a general lack of endorsement of consumer health informatics technologies by medical and healthcare providers is a significant challenge (Slabodkin, 2016). Interestingly, though, evidence is lacking to support a significant impact of such provider views on consumer attitudes and behaviors. Indeed, a growing number of older physicians and other healthcare providers are embracing consumer health technologies, and younger providers, especially those who are "digital natives," appear to be much more enthusiastic supporters of these tools and solutions (Deloitte, 2013).

Finally, computer and technology literacy are also cited as potential challenges to widespread adoption of consumer health informatics tools, particularly among certain low-literacy consumer subpopulations (Norman & Skinner, 2006). As demonstrated in the examples above, it is likely that in the future, literacy may not have a significant impact on consumer knowledge, attitudes, beliefs, or preferences associated with consumer health informatics tools. This is primarily because technology advances and design enhancements, including miniaturization, ubiquitous network connectivity, voice recognition, cognitive computing, and edge processing will enable consumer health informatics tools to disappear and become passive systems that work automatically. They will require little-to-no active consumer involvement, and over time, the systems will learn to understand consumer attitudes, language, and behaviors better.

Summary and Conclusions

Consumer health Informatics emerged as a consequence of the rapid advances of computer technology in society, as well as national demographic shifts and pressures on the traditional healthcare system to provide convenient, cost-effective care to all. The early evolution of the field has been dominated by mHealth, wireless, wearable and simple sensor-based applications, devices, and platforms.

While some of these technologies have been embraced by the public, we are rapidly approaching a saturation point that represents the largest number of consumer health informatics devices an individual consumer can effectively use at any given time. Fortunately, widespread deployment and adoption of broadband networks, along with miniaturization and edge computing, are enabling robust connections between consumer health technologies and platforms to enable the creation of consumer health ecosystems of support that are built directly into the consumers' environment and work automatically in the background to support patient needs.

To ensure universal benefit from these tools, it will be important to maximize broadband deployment and adoption. It will also be important to enhance the design of emerging systems so that they are maximally usable by all consumers. It is also important to address privacy and security concerns associated with these systems.

If these challenges are not addressed adequately, it is likely that the health benefits will be seen among some user populations and not in others. In turn, this could lead to increased gaps or increased health disparities across patient populations.

On the other hand, if we seize the opportunities and overcome the challenges, the possibilities for consumer health informatics to improve health and health equity are transformational. For example, smart homes will monitor asthmatic children's physiologic signs and symptoms at night and automatically administer medications to prevent asthma attacks. Low-cost, wearable wristwatches will help diabetic people monitor their blood glucose levels. Smartphones with enhanced audio features that can easily increase font size will deliver medication reminders for those with limited vision and hearing, and new start-ups will provide home delivery for prescriptions in every neighborhood.

We have previously suggested that health IT devices and applications could undergo voluntary certification for cultural, linguistic/literacy, and human factors for use with high-risk individuals and communities of color (Gibbons, 2011). There may also be value in looking beyond strategies that rely on providers or consumers to actively engage or exhibit a given behavior to strategies that work at a higher level. For example, instead of encouraging consumers to purchase or rent smart homes that could assist with health challenges as described above, it may prove to be far more effective to work with commercial and residential architects and developers to get building codes revised to ensure that the necessary infrastructure is built into all new construction, renovations, and rehabilitations. As such, over time, all housing stock would have the necessary components to ensure that house would be smart, regardless of who bought or lived within it.

This approach may also be helpful for the smart car and mobile home industries as well as many others. Thus over time, we may substantially reduce health disparities and realize significant national health gains that have been historically unachievable.

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Chapter 3
Using Information Technology at Kaiser Permanente to Support Health Equity

Ronald L. Copeland, Winston F. Wong, Jason Jones, and Margo Edmunds

Kaiser Permanente: Toward Health Equity for Individuals and Communities

Kaiser Permanente is the largest not-for-profit integrated health care delivery system in the USA, with more than 11 million members in eight states and the District of Columbia (Kaiser Permanente, 2016a). Headquartered in Oakland, California, Kaiser Permanente evolved from industrial health care programs for shipyard, construction, and steel mill workers in the 1930s and 1940s to its present form.

Today, Kaiser Permanente is a mutually exclusive partnership and contractual alliance among a not-for-profit insurer, Kaiser Foundation Health Plan, a not-for-profit hospital system, Kaiser Foundation Hospitals, and eight physician organizations, the Permanente Medical Groups (Crosson & Tollen, 2017). In each of Kaiser Permanente's geographic regions, the Health Plan offers coverage and the associated Medical Group provides or arranges for professional services for a negotiated per-member fee. Together, the entities that make up Kaiser Permanente employ about 21,600 doctors, 54,000 nurses, and 199,300 technical, administrative, clerical, and caregiving employees at 38 hospitals and 661 medical offices (Kaiser Permanente, 2016a).

Kaiser Permanente's mission is "to provide high-quality, affordable health care services to improve the health of our members and communities we serve" (Kaiser Permanente, 2017a). This paired focus on the health of individuals and the communities in which they live is driven by an understanding that health is "produced" by much more than medical care; it also comes from living in a healthy social,

R. L. Copeland · W. F. Wong (✉) · J. Jones
Kaiser Permanente, Oakland, CA, USA
e-mail: Winston.F.Wong@kp.org

M. Edmunds
AcademyHealth, Washington, DC, USA

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economic, and physical environment (McGinnis, Williams-Russo, & Knickman, 2002) (Fig. 3.1). This perspective is embodied by Kaiser Permanente's vision of "Total Health"—an imperative to re-imagine all business units and the entire workforce, as well as patients, communities, and partners, as producers of health, affecting upstream social, economic, and environmental determinants of health.

Kaiser Permanente's commitment to individuals and communities also derives from the organization's core value of health equity, which has two major components: (1) the notion that the organization's own patients (called "members") must have equal access to the highest-quality care, regardless of socioeconomic or any other factors; and (2) the notion that health systems must address unhealthy environmental factors that disproportionately pose barriers to both members' and the larger community's ability to thrive.

Beginning in 2003, congressionally mandated national reports on health care quality and disparities have tracked non-clinical variations in access and care delivery associated with race, ethnicity, and socioeconomic status (Moy, Dayton, & Clancy, 2005). The most recent report found that access and quality of care were improving, but wide variations and health disparities continue (Agency for Healthcare Research and Quality, 2016). The development of indisputable evidence of disparities has been facilitated by an ever-evolving research infrastructure and new analytic methods to summarize, standardize, and report disparities across measures and settings (Moy et al., 2005). For example, the development of geocoding and spatial analysis has helped to identify "hot spots" where individuals and communities experience a disproportionate share of chronic disease, helping planners

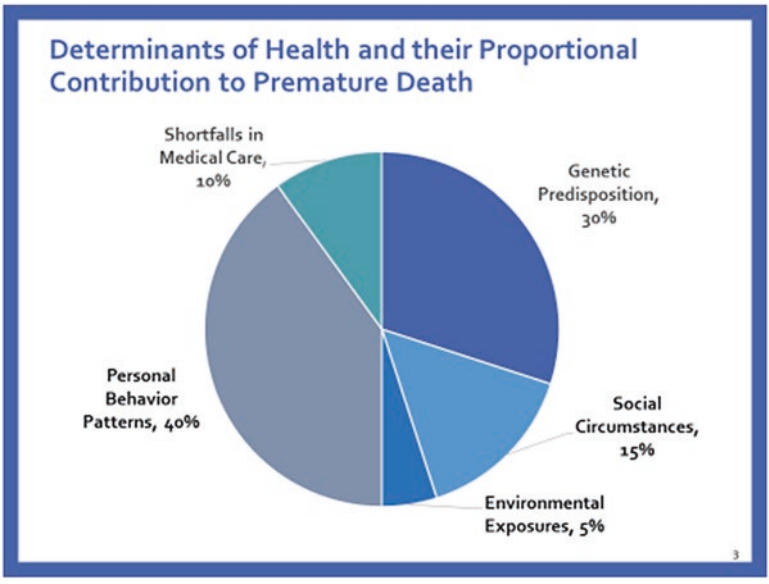

Fig. 3.1 Health is influenced by many factors in addition to medical care. Source: Adapted from McGinnis et al. (2002)

and health systems target resources where the need is greatest (Columbia University Mailman School of Public Health, n.d.).

Investments in electronic health records (EHRs) also contribute knowledge about health disparities (Diamond, Mostashari, & Shirky, 2009), particularly when combined with data from sources such as vital statistics and registries. Kaiser Permanente was one of the first health care systems to implement a comprehensive EHR and to develop clinical analytics (Burns, 2014), allowing the organization to provide national thought leadership and models for leveraging information technology (IT) to help address health disparities.

Health IT is a key feature of Kaiser Permanente's care delivery strategy, the goal of which is to provide customized care, taking into account not only clinical needs, but also aspects of a patient's and community's social background—vital components of health and wellness. This chapter discusses health information technologies that engage patients and physicians, raising the bar on health care quality for all and thereby improving health equity.

Addressing Health Equity Among Kaiser Permanente Members

Kaiser Permanente has made a national commitment to reducing disparities related to members' age, gender and gender identity, sexual orientation, geography, ethnicity, language, and cultural background. The organization's members speak nearly 200 languages and come from diverse communities with unique beliefs about health and many different values and traditions. To care for this diverse population, the organization provides its physicians and clinical staff with training and support tools.

Nearly 20 years ago, workforce training focused on cultural competency and was built around a series of manuals addressing the specific care needs and preferences of different populations. Today, the focus on cultural competency has given way to a focus on "cultural humility"—the notion that it is less important for clinicians to know, in advance, what cultural issues might come into play with a given patient based on his ethnicity, but rather that they should be skilled in asking questions to elicit culturally informed care goals and preferences from all patients. To support physicians and staff in focusing on culturally and linguistically appropriate care, Kaiser Permanente also has a strong commitment to inclusive leadership and training in cross-cultural agility—a learnable skill (Caligiuri, 2012).

This section illustrates how Kaiser Permanente's use of IT and analytics has enabled the organization to address disparities among its members—by allowing it first to *detect* them. Next, it describes the many ways that Kaiser Permanente harnesses IT to work toward reducing disparities.

Identifying the Problem: Detecting Disparities

Historically, one of the greatest challenges facing Kaiser Permanente—and any delivery system committed to reducing health disparities—was a lack of meaningful and accurate data on patient ethnicity and language. (The Meaningful Use EHR Incentive program did not require providers to collect such data until 2011 [Office of the National Coordinator for Health Information Technology, 2014].)

Prior to the adoption of advanced health IT, Kaiser Permanente could obtain *some* information regarding disparities among groups of members, but data sets were not uniform. Patient identification of ethnicity and/or language preference was not standardized system-wide, leading to gaps and inconsistencies, as well as a data collection process that was expensive, fragmented, and not used to drive systematic performance improvement.

The lack of a uniform database permitted only partial analyses of gaps in care related to ethnicity and race, which were grouped according to the prevailing six categories used by the Office of Management and Budget (OMB): American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Other Pacific Islander, and White (Office of Management and Budget, 1997). However, analysts found the effectiveness of this approach to be limited. In 2004, as part of a national collaborative among health plans, Kaiser Permanente began working with researchers from the RAND Corporation to implement a predictive model to impute race/ethnicity for groups of patients based on both surnames and census tract information. The methodology did not "assign" ethnicities to individual patients, but rather allowed the organization to track care and outcomes for *groups* of patients.

The imputed methodology worked well for Kaiser Permanente. It allowed leaders to see, for the first time, clear evidence of disparities in clinical outcomes and processes associated with differences in race and ethnicity across Kaiser Permanente's eight operating regions and collectively as a national organization. This finding provided the impetus for the organization to invest resources in incorporating a question about patient self-identification of race and ethnicity into patient intake protocols.

Initially, Kaiser Permanente was able to obtain ethnicity data from about 50% of members and continued to rely on the imputed methodology for the rest. Today, Kaiser Permanente leaders estimate that they have patient-reported language and ethnicity data from close to 90% of members. To maintain statistical validity and external generalizability, most analyses of disparities group patients into the OMB's six mega-categories.

However, Kaiser Permanente's systems collect the information in such a way that, if needed, the organization can drill down below those categories to look at information for 240 categories of ethnicity that are used by the United Nations. Ultimately, the EHR now provides Kaiser Permanente with a richly layered profile of membership—including vital demographic data—that is constantly refreshed and can reveal patterns of disparities in processes and clinical outcomes.

The organization has incorporated equity measures into its national "quality dashboard" for senior leaders and also produces quarterly equitable care reports—comprised of 24 quality measures that are stratified by the OMB's six categories of race/ethnicity (Table 3.1). These measures align with the organization's national quality priorities and focus on areas that have been shown in the research literature to have significance for disparities. The equitable care reports ensure that equity is maintained or improved as overall performance improves.

Addressing the Problem: Using Technology to Support Member Health and Health Equity

Kaiser Permanente's member-centered, coordinated health IT ecosystem combines tools, resources, processes, and workflows in an integrated environment. Implementation of the EHR—known as HealthConnect®—made it possible for Kaiser Permanente to gather clinical information from visits, labs, pharmacy, and all other sources in one place. The EHR is itself integrated with population health management tools, patient/provider interfaces, and administrative and consumer support systems (Fig. 3.2). All of these systems, as well as other information technologies that support member health and health equity, are described in this section.

In many cases, the systems and processes described here were developed using human-centered design principles. A cornerstone of innovation at Kaiser Permanente, human-centered design brings together the people who will use a new service, product, or technology to co-design it with those who will deliver it. In practice, this

Table 3.1 Kaiser permanente tracks 24 equitable care measures

Prevention and screening	*Cardiovascular conditions*	*Diabetes*
• Breast cancer screening • Cervical cancer screening • Colorectal cancer screening • Childhood immunization status • Immunizations for adolescents • Human papillomavirus vaccine for female adolescents	• Persistence of beta-blocker treatment after a heart attack • Controlling high blood pressure statin therapy for patients with cardiovascular disease: −Received Statin Therapy −Statin Adherence 80%	Comprehensive diabetes care: • HbA1c testing • HbA1c s≤ 9.0% • HbA1c < 8.0% • Retinal Eye Exam • Medical Attention for Nephropathy • BP < 140/90 Statin therapy for patients with diabetes: • Received statin therapy • Statin adsherence 80%
Behavioral health	*Medication management*	*Respiratory conditions*
Antidepressant medication management: • Effective Acute Phase Treatment • Effective Continuation Phase Treatment	Annual monitoring for patients on persistent medications: • ACE or ARB • Digoxin • Diuretics	• Asthma medication ratio

Source: National Health Plan & Hospital Quality, Kaiser Permanente. Used by permission

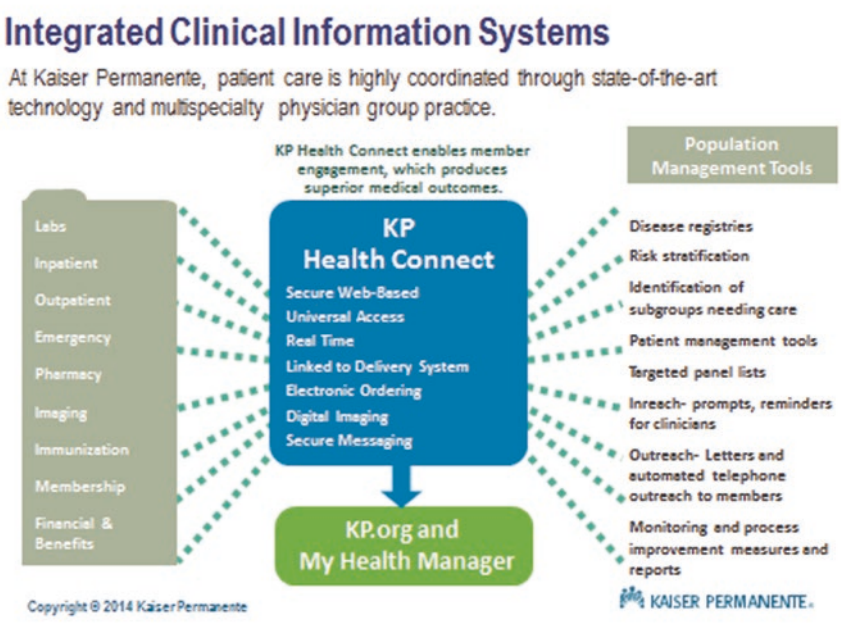

Fig. 3.2 Kaiser Permanente's integrated clinical information systems support member health. Source: Kaiser Permanente. © Used by permission

means that patients are often involved in the design of patient-facing materials and tools, and physicians are similarly involved in the development of tools intended for their use.

Electronic Health Records: HealthConnect®

In 2010, Kaiser Permanente completed the implementation of HealthConnect, the largest civilian EHR in the USA. HealthConnect is more than just an electronic medical record; it is an organization-wide system that integrates the clinical record and decision support with appointments, ancillary and specialty services, registration, and billing.

HealthConnect supports a patient portal (see below) and serves as a personal health record for members and others receiving care at Kaiser Permanente. Inputs from laboratory, imaging, pharmacy, membership, and other departments support population-management activities, such as disease registries and risk stratification calculators. The system also supports quality-improvement efforts and generates reports that promote conversations with providers about their performance relative to that of their peers in clinical quality, safety, efficiency, equity, and service.

Deployment of HealthConnect meant replacing multiple legacy systems in use across Kaiser Permanente, some of which were well established. In fact, in the late 1990s, three different Kaiser Permanente regions received the Davies Award from the Health Information and Management Systems Society (HIMSS) for implementing EHRs. When leaders made the difficult decision to bring all regions onto the same EHR, the organization evaluated several products that proved unable to support the complex needs of the organization (with eight million members at that time). Ultimately, Kaiser Permanente selected a commercial EHR vendor to build HealthConnect, but it still required seven years and approximately $4 billion—the largest capital project in the organization's history. By comparison, the most recent hospital completed in the Kaiser Permanente system (in 2017) cost $850 million and took three years.

Successful roll-out of the system was a top priority for leadership and required a high level of commitment from all parts of the organization. Implementation of the EHR has brought about significant workflow change at Kaiser Permanente, particularly for the physicians and other staff who interface with the tool. Leaders found that technical implementation was necessary but insufficient. It was also necessary to focus on user-centered design and training in the context of workflow. Often, the workflow itself needed to be altered to take advantage of the technology to achieve net benefit.

Ultimately, Kaiser Permanente's goal is to use the EHR to transform care and service delivery. From a quality perspective, connecting care teams with patients and with consistent, organized, prioritized information makes decision-making and care management easier. Kaiser Permanente's experience with HealthConnect demonstrates that making comprehensive health information available to all clinicians, as well as to patients, provides the foundation for a fundamental rethinking of the delivery of health care—who provides care, how care is provided, and what care outcomes are achievable (Liang, 2010).

As one of the earliest (and largest) adopters of comprehensive EHRs in the USA, Kaiser Permanente has played an important leadership role, both here and around the world, in developing industry standards for the use of such tools. Kaiser Permanente holds leadership positions in multiple national and international standards development efforts and organizations, such as Health Level 7 International (HL7), OASIS, the American National Standards Institute, the International Organization for Standardization, and the World Wide Web Consortium. The organization also influences health IT standards by providing input to regulatory agencies and industry groups through comment letters, testimony, and participation in advisory bodies.

Provider-Facing Population Health Management Tools

The EHR is integrated with population and panel management systems used by physicians and staff. Panel management is a set of tools and processes for population care applied systematically at the level of primary care (Neuwirth, Schmittdiel,

Tallman, & Bellows, 2007). Specific tools vary across Kaiser Permanente, but the basic components are the same, as is the goal—to empower team members, whether they are primary care physicians, specialists, or staff members, to identify and address gaps in care across the entire member population.

In Kaiser Permanente's Southern California region, clinicians use a system called Permanente Online Interactive Network Tools (POINT) to identify and address care gaps (Kanter, Lindsay, Bellows, & Chase, 2013). The system integrates clinical data from the EHR and uses an algorithm to identify patients with chronic disease who are "missing" needed treatments or tests, based on best-practice guidelines.

The system can generate a chronic care summary sheet, providing physicians with high-level information about the treatment and monitoring of chronic conditions among their panel of patients. It also creates point-of-care alerts in the EHR and prompts all team members—from physicians to pharmacists to receptionists—to offer the missing care to patients during each encounter (this "inreach" strategy, called the "Proactive Office Encounter," has been particularly successful in closing gaps in both chronic and preventive care in Kaiser Permanente Southern California [Kanter, Martinez, Lindsay, Andrews, & Denver, 2010]). To help close care gaps for patients who may not have had a health system encounter recently, the system creates risk-stratified follow-up lists so that staff can reach out to them proactively by phone or other methods.

Disease registries are another important tool in panel management. Using data extracted from the EHR, a disease registry is a list of all patients in a given practice (or medical center or a larger region) who have a specific condition or procedure. Such registries support quality-improvement initiatives for target populations that are identified by local clinical leaders; for example, diabetic patients with hemoglobin levels higher than the desired threshold. Working with these registries, staff members review selected patient charts, identify opportunities to align care with evidence-based guidelines, and initiate protocol-based orders for tests or medication (Kanter et al., 2013). Physicians then either approve or modify these orders.

A critical aspect of population health management tools is that they are shared by all clinicians and staff providing clinically oriented service to members. As such, these tools support the entire delivery system in preventing gaps in care, or closing those gaps wherever and whenever they may become evident—not solely during primary care visits.

Patient Portals: My Health Manager

While population health management tools support clinicians and staff, Kaiser Permanente also employs a variety of technologies to help patients play a role in their own care. Perhaps most important among these is the patient portal, My Health Manager.

In the late 1990s and early 2000s, Kaiser Permanente was among early adopters of patient portals or electronic tools for patient-centered communication. The organization's first informational patient website became interactive in 2003, when the Northwest region (Oregon and Washington) piloted a new functionality that allowed secure member access to parts of the EHR. Today, an online portal called My Health Manager is available in all Kaiser Permanente areas and can be accessed by registered and authenticated users through the website www.kp.org or through a mobile app. Registered members can use it to send and receive secure email with their physicians, schedule routine appointments, view past visit information, refill most prescriptions, see most lab test results, and access plan/payment information and health education materials. In 2015, about 70% of eligible Kaiser Permanente adult members, or 5.37 million people, had registered to use My Health Manager (Garrido, Raymond, & Wheatley, 2016).

Kaiser Permanente has found that use of secure email between providers and patients is associated with improved outcomes and stronger patient-centered care. Use of email is associated with a 2–6.5% improvement in Healthcare Effectiveness Data and Information Set (HEDIS) performance measures (Zhou, Kanter, Wang, & Garrido, 2010). In a 2011 internal Kaiser Permanente study, nine out of 10 patients with chronic conditions said My Health Manager enabled them to manage their conditions more effectively.

Patient portal use also raises patient satisfaction and loyalty to the health plan. Internal Kaiser Permanente research indicates that members who emailed their primary care providers reported high satisfaction with their email experiences (85% rated email encounters an 8 or 9 on a 1-to-9-point scale). My Health Manager users are also 2.6 times more likely to remain Kaiser Permanente members than are non-users (Turley, Garrido, Lowenthal, & Zhou, 2012).

At Kaiser Permanente, the impact of secure email use on other types of utilization, such as office visits and telephone contacts, is complex. Though various studies' findings have been inconsistent (Meng et al., 2015; Palen, Ross, Powers, & Xu, 2012; Reed, Graetz, Gordon, & Fung, 2015; Zhou, Garrido, Chin, Wiesenthal, & Liang, 2007), internal research shows face-to-face visits per member per year have fallen slightly while secure email visits per member per year have risen substantially, suggesting that technology is increasing access to primary care by allowing more contact with patients than in the past (Garrido et al., 2016).

Despite their benefits, there is a concern that patient portals create their own type of disparities by disproportionately benefitting people with access to technology and the skills to use it. Kaiser Permanente tracks this issue closely. Internal research has found the following regarding use of My Health Manager: members with the highest registration and use rate are between 60 and 69 years old; registered members are more likely to be white (non-Hispanic) than those who are not registered (Roblin, Houston, Allison, Joski, & Becker, 2009); and even after adjusting for age, gender, income, and other factors, Asian Americans, Latino Americans, and African Americans were 23%, 55%, and 62% less likely to register, respectively, than non-Hispanic whites (Garrido et al., 2015).

Multimedia Patient Education Tools

Kaiser Permanente deploys a wide variety of multimedia tools to help educate patients about health issues, often targeting areas of known health disparities. For example, internal data around clinical process measures spurred a Kaiser Permanente Northern California effort to improve colorectal cancer screening among Latinos. (Disparities between whites and Latinos in colon cancer screening have been well-documented nationwide [Jackson, Oman, Patel, & Vega, 2016.])

The project's goal was to increase the rate of Latino members who complete a noninvasive, in-home screening called the fecal immunochemical test ("FIT kit"). To accomplish this, the organization worked with Latino members to co-design, in Spanish, the FIT kit instructions and materials. As a part of this human-centered design process, member-advisers also helped design a Spanish-language instructional video (available online and in clinics) and a series of photo novellas to explain the importance of screening and demonstrate how to use the screening test at home.

Member involvement in the process led to identification of culturally relevant nuances that might otherwise have been missed. As a result of these and other efforts across Kaiser Permanente Northern California, the gap between the FIT screening rate for white members and Latino members decreased by 16% over a one-year period (Radding, 2017).

Mobile Apps

Increasingly, mobile apps are becoming an important tool for Kaiser Permanente to connect with members apart from visits to a health care facility. The organization's interest and work in mobile apps stems from a desire to make care more convenient for members and to "meet them where they are." While there are literally thousands of mobile apps that can help people stay healthy or manage chronic conditions, Kaiser Permanente has focused its development efforts on those that interface with the organization's EHR. For example, the previously noted My Health Manager mobile app has almost all the functionality of the My Health Manager web portal (see "Patient Portals," above), including secure email with providers, appointment scheduling, prescription refills, and access to some lab results.

"MyKPMeds," an EHR-connected app used in Kaiser Permanente's Northern California and Mid-Atlantic States regions, helps members manage complex and/or new medication regimens. Kaiser Permanente first piloted MyKPMeds with patients who had been discharged from the hospital, as post-discharge medication error is a major contributor to re-hospitalization.

Since then, the organization has found that it is also effective for patients—such as those with HIV—who have ongoing and complex medication regimens, or for those who face non-medical barriers to medication adherence, such as food or housing insecurity. MyKPMeds provides registered users with a list of their medications (including photos of each pill) and gives them the option of setting alarms when it's time to take each one. Members can also refill prescriptions through the app. Most

importantly, if the provider changes the regimen—either during an office visit or through a phone or email consult with the patient—and the change is made in the EHR, the information in the app is automatically updated.

Mobile apps can be especially important in helping Kaiser Permanente providers stay continuously engaged with more vulnerable patients—those who, due to medical or social circumstances, may find it difficult to schedule and keep face-to-face health care appointments. Research indicates that in 2015, fully 77% of US adults owned a smartphone, and that rate varies only slightly by ethnicity and income (Pew Research Center, 2017). As a result, Kaiser Permanente views mobile apps as a means of providing a broad cross-section of members with additional points of access and support.

Telehealth

While definitions of "telehealth" services vary, most include at least three broad categories, all of which are used at Kaiser Permanente: 1) audio, visual, or web-based technologies that facilitate two-way, real-time communication between patients and providers (e.g., telephone and video visits); 2) remote monitoring that allows providers to observe patients, using telecommunication technology (e.g., a patient transmitting blood pressure data to a provider using a wearable device); and, 3) asynchronous "store-and-forward" technology that transmits information from patients to providers or among providers without requiring simultaneous engagement (e.g., a provider transmitting an EKG to another provider for review and diagnosis). The goal is to remove time- and distance-related barriers to care.

Kaiser Permanente's use of secure email between patients and providers is discussed above (see *Patient Portals*). In addition, the organization offers patients the option of a telephone visit in many circumstances, often with no patient copay. In 2015, Kaiser Permanente members had 36.7 million telephone encounters with doctors, support staff, and other care team members (Kaiser Permanente, 2016b). In some specialties, digital photography and video-enabled visits are also available. For example, Kaiser Permanente first began using photography for remote consults in dermatology as a tool for primary care physicians to confer with specialists in near-real time. The organization also uses video in dermatology, either as a means for patients to check in with providers from home or for a dermatologist to connect with a patient and a primary care provider in real time during a primary care visit (Wheatley, 2015).

Today, video visits for primary care, neurology, mental health, and other specialties are in various stages of development and deployment at Kaiser Permanente. Patients connect with providers via video using a secure application that interfaces with the EHR. This technology holds particular promise for the care of patients recently discharged from the hospital. The video connection can be facilitated by a home health nurse, if needed, giving the physician an opportunity to observe the home environment to better understand any factors (including social factors) that will help or hinder the recovery process.

For routine care, video and telephone visits are especially useful in situations when members' work, school, or family caregiving responsibilities prevent them from attending in-person appointments during regular office hours. Video and telephone visits can save members and the organization the extra expense that would otherwise be associated with an after-hours urgent care visit or an unnecessary visit to the emergency room for care that does not require such a setting.

For patients with chronic conditions, Kaiser Permanente is piloting another telehealth technology: remote in-home monitoring. For example, one pilot focuses on glucose levels in people with diabetes, and one focuses on blood pressure levels in people with hypertension. In both cases, the patient wears a monitoring device that transmits data via Bluetooth through a receiver to the physician, using the EHR. In the future, this platform may be useful for monitoring other conditions, such as sleep apnea.

To some extent, legal and regulatory barriers limit the ways Kaiser Permanente—and other providers—can use telehealth tools. One important barrier is related to payment. Medicare's traditional fee-for-service program pays providers for care furnished using telehealth technologies only in rural areas. However, Kaiser Permanente serves the Medicare program primarily as a capitated Medicare Advantage plan, and as such, may provide telehealth services but must categorize them as "extra services." This means a potential reduction in other extra benefits or higher member premiums. In addition to Kaiser Permanente, several coalitions, including the Coordinated Care Coalition and the American Telemedicine Association, are working to influence policymakers to expand the use of remote access technologies in Medicare (Wheatley, 2015).

State medical licensing laws can also present a challenge for the use of telehealth by delivery systems, such as Kaiser Permanente, that span multiple states. Such laws bar physicians and other clinicians from providing services to people outside of the state in which they are licensed. The Federation of State Medical Boards has introduced an Interstate Licensure Compact that creates a new licensing option under which qualified physicians seeking to practice in multiple states could obtain expedited licensure in all states participating in the Compact (Wheatley, 2015). In the meantime, some Kaiser Permanente physicians obtain licenses in multiple states. This is particularly common in the Mid-Atlantic region, where patients often cross state borders (e.g., Virginia and Maryland) and travel to other states for extended periods(e.g., retired members living in Florida for the winter).

Implications for the US Delivery System

Kaiser Permanente is often considered an anomaly in the health care industry, given its structure and prepayment model, as well as its emphasis on prevention, population health management, community health, health equity, and the use of technology to augment whole-person care. However, over the past decade or so, there is growing awareness and acceptance of these principles from other health care

stakeholders. Most recently, there have been a series of "nudges" from federal and state health policy leaders that signal movement toward more integrated and coordinated care, with value prioritized over volume. The shift from volume- to value-based health care is driving an increased interest in managing the health of populations by targeting interventions to the right people at the right time (Numerof, 2015), an undertaking that requires a capacity for sophisticated analytics.

Kaiser Permanente's unique organizational structure and prospective payment model create a compelling business case for the organization to invest in the IT infrastructure necessary to manage population health and address disparities. However, other delivery systems that operate under different payment arrangements—and that do not have such a well-defined "member" population—also need to move in this direction, and many are doing so.

In fact, one could make the case that there are ways in which less integrated care and coverage models have an advantage over Kaiser Permanente in terms of using IT to support whole-person care. There has been pressure on them to develop capabilities to transfer data and information across organizational boundaries—among providers, from provider to payer, and the like. Such interoperability among delivery system stakeholders is critical to providing coordinated care.

Whether the term "population" is used to refer to people who live in a certain geographic area, who have a certain medical condition, or who belong to a particular health plan, population health management calls for the vision and tools to provide care for individuals and groups, both within and outside of traditional clinical settings. One of the fastest-growing areas in health systems and clinical analytics is the integration of claims data (from legacy systems) and clinical data from EHRs to improve performance, identify gaps, and improve patient care and safety.

A recent HIMSS analytics survey found that 80% of surveyed organizations with 100 or more beds are undertaking population health planning and patient-centered analytics (Health IT Analytics, 2015). For smaller practices, the current focus is more on joining an accountable care organization, expanding an integrated delivery network, or looking into the new EHR-based tools. The market for population health management tools is predicted to double by 2020, when it could reach nearly $32 billion (Tractica, 2015).

Conclusion: Challenges and Opportunities Ahead

Kaiser Permanente's technology-supported care delivery strategy reflects the knowledge that good medical care is necessary but insufficient for achieving health. Good health requires community engagement, both to understand what communities want from delivery systems and because delivery systems rely on community assets to deliver on their mission.

This chapter has illustrated how technology can help delivery systems broaden access, close care gaps, and reduce disparities. However, there remain significant

questions and challenges in optimizing technology to improve health. As such, Kaiser Permanente leaders are focused on the following imperatives:

- *First, do no harm.* Evidence from sectors outside of health care indicates that technology divides people and can increase disparities. How do we ensure that technology improves overall quality, of which equity is a key component? Going forward, Kaiser Permanente must continue to identify where utilization of health technologies may have disproportionate benefit to those who are already socially advantaged, lest it exacerbate or create new disparities. The distribution of technology is, in and of itself, an opportunity to enhance equity or contribute to yet another layer of challenges which give rise to unequal outcomes. Ultimately, the benefits or harm associated with technology will be determined by Kaiser Permanente's fidelity to its underlying organizational values of inclusion and diversity.
- *Measure what matters*. Delivery systems have become adept at classifying patients (e.g., with ICD-10 codes), capturing actions to support them (e.g., with CPT codes), and measuring performance (e.g., with HEDIS). However, as of yet, there is no systematic way to capture a person's circumstances (e.g., burdened by automobile expenses), preferences (e.g., dislikes the idea of chronic medication), or goals (e.g., wants to complete a 5 k run). Can technology help close these information gaps? Can it be effective in achieving equitable health if the gaps persist?
- *Know what works best*. Technology of the type discussed in this chapter changes much more rapidly than other tools in the care delivery system. How do we understand both what works and how to optimize the use of these tools in the context of alternative and complementary assets?

If delivery systems can address these questions, they have a better chance of leveraging technology to engage members and communities in preserving and improving health. Doing so will also require a strong cadre of health care providers who understand the power of community health and are committed to working with diverse partners.

To that end, Kaiser Permanente will open the doors of an innovative medical school in the fall of 2019. One of the school's explicit goals is to increase diversity and promote inclusion in the physician workforce and improve the health of underserved populations. In addition to clinical learning, the curriculum will emphasize health equity, community service, and leadership. It is also part of the organization's vision for the school to be a transformative force in medical education by incorporating technology more fully into the learning process. Accordingly, the medical school will provide a technology-enhanced learning environment, including augmented and virtual reality tools to teach anatomy and digitalized clinical case studies integrated with gamification techniques and accessible through multiple access points to enhance team discussion, without need of formal lecture halls.

Finally, it is important to return to a point from the start of this chapter—that social and environmental factors, as well as personal behavior, play a much larger role in health than does medical care. That is why Kaiser Permanente's mission is to

serve not only its members, but also the communities in which they live and work. Without healthy and supportive communities, people cannot thrive. Sadly, the USA as a whole vastly underinvests in the "social care" services that support health, compared to most industrialized nations (Squires & Anderson, 2015). Kaiser Permanente leaders believe that, to be effective, health care delivery systems must address this shortcoming and have an obligation to do so. In 2016, Kaiser Permanente distributed nearly $82 million in grants to community-serving organizations (Kaiser Permanente, 2017b).

Going forward, leaders hope to build upon information technologies that support high-quality, equitable care for members, leveraging them to address gaps in social care as well as health care, and benefitting communities more broadly. This will require financial and human investments, as well as strategic partnerships with other health systems, community service providers, and the public sector.

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Chapter 4
Healthcare Social Media for Consumer Informatics

Mandi Bishop

Introduction

If you're reading this, chances are you're a digital native—born in the Information Age, raised on smartphone apps, speaking fluent text acronyms and emoticons. It's likely that the internet is the first source you turn to for research on every topic from "how to apply the perfect smoky eye makeup" to the nuanced politics of the Middle East.

It may be tough to imagine a time when instant information access was not available, any time, on demand, at your fingertips. But I was born in such a time: when research had to be done at a physical library, during library hours, using the Dewey decimal system to navigate rows of shelves and find encyclopedias that were only updated once a year, and whose entries referenced other physical books that I then had to go back to Dewey to locate (see Fig. 4.1). Crowd-sourced information stores, such as Wikipedia, existed in different forms within communities—but they were called opinions or rumors, not facts.

As you read, try to remember that the road to digital culture acceptance was a long one—and that, for many individuals and organizations, we aren't there yet. Healthcare, as an industry, has traditionally been a Luddite, lagging a decade or more behind most major industries in the adoption of new technology.

However, in recent years, the industry has been accelerating its technology proliferation—with social media playing a large part in propelling healthcare forward into its inevitable digital future. Consumers have come to expect and demand the digital native experience, and social media gives them a powerful, global voice to ensure these demands are heard and met.

M. Bishop (✉)
Gartner, Jacksonville, FL, USA

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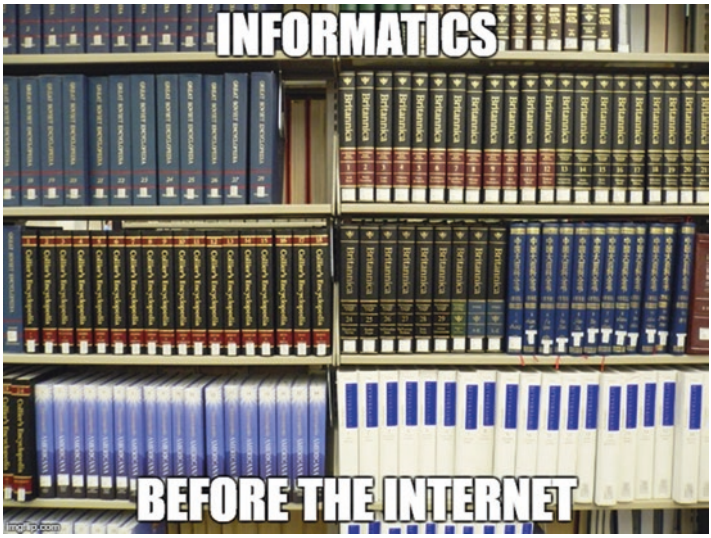

Fig. 4.1 Informatics before the Internet = Encyclopedias. Source: Meme

Historical Context

It could arguably be said that the dawn of consumer informatics corresponded with the birth of the internet, and that increased attention to healthcare consumerism principles and practices over the past decade are partially a result of the rapid proliferation and adoption of social media networks. After all, the internet is a seemingly infinite source of living documents encompassing research and treatment advancements, as well as performance scorecards—enabling instant access to information and expert analysis that once took years, if not decades, to make available to the public.

The rise of what we think of now as "social networks" began in earnest in the 1980s with the introduction of the personal computer and online meeting places called "Bulletin Board Systems" (BBS), which were typically local hubs for file and message-sharing. They were local because the connections between computers used analog phone lines, and long-distance rates would apply for out-of-area calls. CompuServe's consumer market growth in the late 1980s and 1990s further democratized social networking by enabling public access to email and a vast array of discussion forums. In 1993, when America Online created a Windows version of its software and offered internet access in addition to personalized email and member profiles, it paved the way for web-based social networking: Classmates.com and MySpace.com to Facebook and beyond.

Today, merely a decade after Facebook launched to the general public, the majority of US consumers across age groups, genders, races, geographies, and income levels use one or more social networks. According to Pew Research Center's report, "Social Media Update 2016" (Greenwood, Perrin, & Duggan, 2016), 86% of all

adults in the USA are online, and most of them are active on at least one social media network. Figure 4.2 provides a timeline of some of the major events leading up to the current state of social media adoption.

Although platforms like Facebook, Twitter, and Instagram are most likely the platforms that come to mind when considering the question, "what IS social media," there is a much broader definition that is more contextually appropriate in consideration of its position as a modern cornerstone of consumer informatics. *For purposes of this chapter, we define social media as any online resource that is designed to facilitate engagement between individuals.* Social media networks can be available for the general public, such as Facebook, or can be private, such as Yammer, which restricts use to communications within organizations. Worldwide, there are dozens of social media networks vying for users and advertising market dollars (see Fig. 4.3).

For the purposes of this chapter, the focus will be on those networks most heavily used in the USA.

Industry Context: Why Healthcare Is Different

Healthcare has always been a laggard in technology-based innovation adoption, in comparison with other industries, for a number of reasons. First, health care is highly complex and constitutes nearly 18% of the economy in the USA (CMS.gov, 2018), and has many stakeholders with competing ideas about how care should be accessed and provided. In addition, the regulatory landscape for healthcare offers a maze of complexities, with differences between often-conflicting local, state, and federal legislation creating comprehension and compliance challenges.

Due to the intensely personal nature of medical records, the prevailing industry paradigm, until recently, was that information created within the walls of the hospital was to remain within the walls of the hospital. The systems managing information were designed with proprietary programming languages specifically to be incapable of exporting health information to the outside world. Plus, Americans are uniquely litigious; any breach of privacy or the social contract resulting from adoption of technology could result in a lawsuit.

Yet, even with those challenges, healthcare is making its way online.

Platforms

Facebook

Of the online adults in the USA, 68% use Facebook—a user base which transcends age, gender, income, and geography barriers, with 74% of Facebook users accessing the network every day (Pew Research Center, 2018).

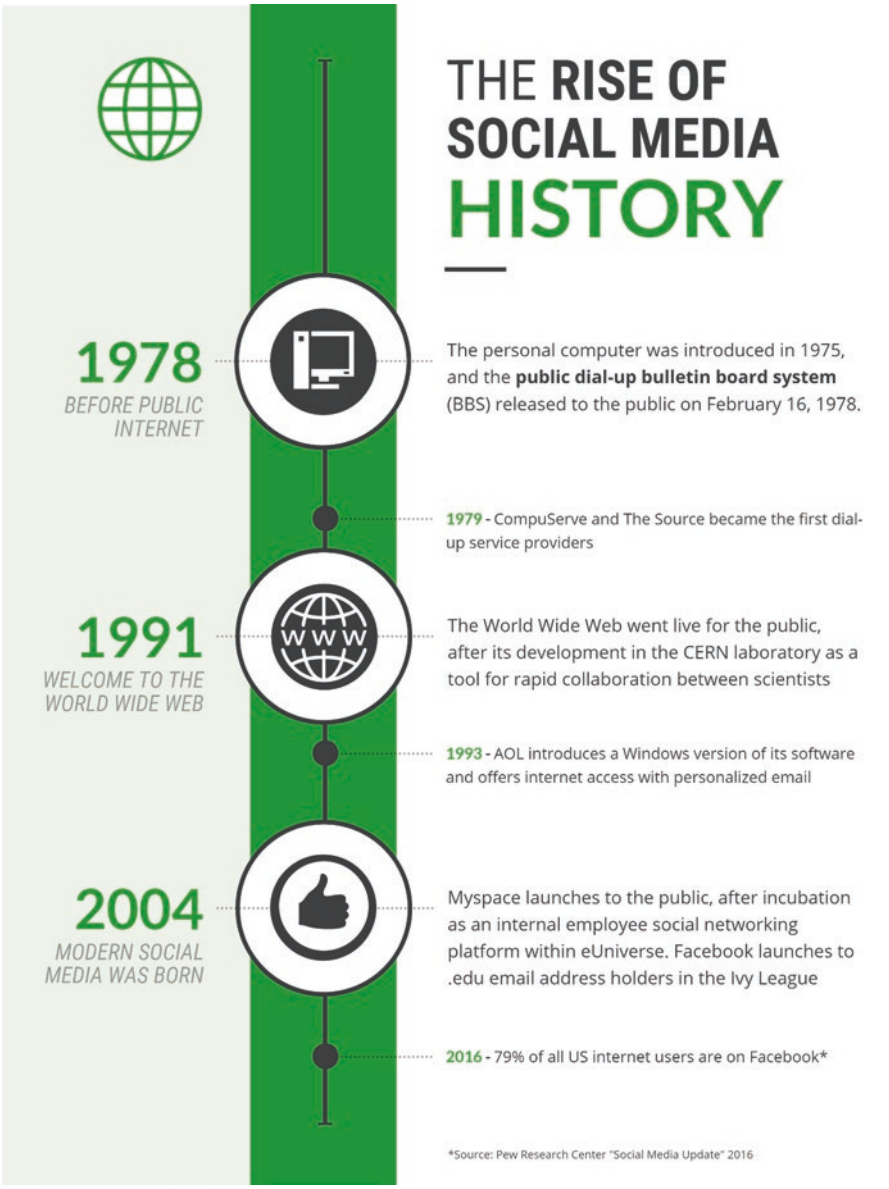

Fig. 4.2 The rise of social media: history. Source: Original graphic created by author using the following sources: 1975 personal computer—Altair 8800 http://historycomputer.com/ModernComputer/Personal/Altair.html; 1978 BBS birth—https://www.theatlantic.com/technology/archive/2016/11/the-lost-civilization-of-dial-up-bulletin-board-systems/506465/; 1979 Compu Serv—https://www.wired.com/2009/09/0924compuserve-launches/; 1991 WWW launch—https://thenextweb.com/insider/2011/08/06/20-years-ago-today-the-world-wide-web-opened-to-the-public/; 1993 AOL personal email—http://time.com/3857628/aol-1985-history/; 2004 MySpace—https://www.huffingtonpost.com/2011/06/29/myspace-history-timeline_n_887059.html; Pew Research Center, Facebook remains the most popular social media platform, "Social Media Update," 2016 http://pewinternet.org/2016/11/11/social-media-update-2016/

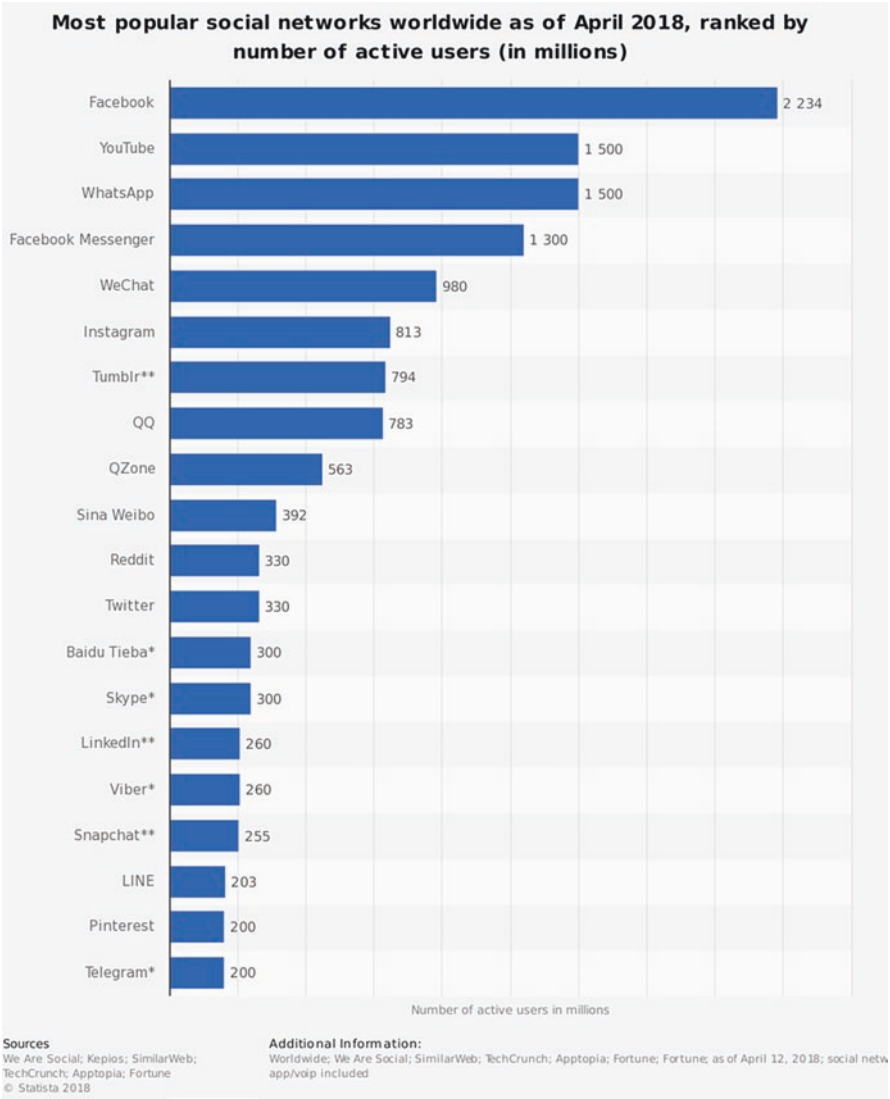

Fig. 4.3 Most popular global networks as of April 2018. Source: (Statista 2018). Downloaded from https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/ Used with permission

Quantitatively speaking, approximately 179,000,000 people are engaging with Facebook content on a daily basis. That means 68% of all US adults, inclusive of the entire population—including those with and without internet access—are Facebook users. They are online, engaging with each other and with companies (or brands) via Facebook profiles, pages, groups, events, and messages—and a growing number of them are actively seeking and sharing health and healthcare information.

The volume of content Facebook users create, curate, and engage with on a daily basis is staggering. According to TechCrunch (Constine, 2016), Facebook had over 2.5 trillion posts in 2016. When Facebook introduced keyword search capabilities across its entire content base in 2015, it opened a Pandora's Box of possibilities for consumers searching for healthcare-related information. Regardless of the search term applied, it is likely that there is a related public post available for the user to view and potentially share with her family, friends, neighborhood, or physician.

While these billions of users may post or read health-related content in the course of their Facebook newsfeed browsing, features allowing users to create private groups and events, giving individual administrators the control to restrict membership and moderate content, have provided the opportunity for thousands of specific healthcare-related virtual communities to grow. Bloomberg reported in 2016 (Frier, 2016) that over one billion people use Facebook groups, with users leaving ten billion comments and "liking" 25 billion-plus pieces of content. Newer features, such as file-sharing and member solicitation via email rather than Facebook interface, are expected to further increase group and event product use in 2017 and beyond.

Group engagement increases both site visits and the length of each visit, both desirable conditions for increased marketability to advertisers and shareholders. According to Statista, a research aggregator, in February 2018 (Statista, 2016), Facebook accounted for 42% of all social media visits, with Twitter at a mere 5.2%. LinkedIn, a professional networking site, garnered a mere 1.2% (see Fig. 4.4).

Given these usage statistics, it shouldn't be surprising that it is likely that there is at least one Facebook group dedicated to the specific type of information a healthcare consumer might seek. Facebook's market dominance, in addition to its searchable content features, makes it one of the top online resources. Rare disease sufferers and their caregivers can find groups to search and share details about treatment regimens, such as those seeking information about epidermolysis bullosa, a disease affecting approximately 20,000 people in the USA, and with no fewer than 5 dedicated Facebook group resources. Physician mothers sharing tips and tricks have over a hundred groups available to join. Health systems, individual physicians, and insurers all have the opportunity to create individual profiles, pages, groups, and events, which can address a particular topic (such as a diabetes management program) or a particular function (customer service).

New social media platforms are introduced regularly. However, the market share discrepancy between Facebook and its competitors is so large, it would take a disruptor of Amazon proportions to overtake them.

Twitter

Twitter, founded in 2006, was designed as "the text-messaging of the internet" (Wikipedia, 2017a, 2017b), a platform from which registered users could share "short bursts of inconsequential information" in 140 characters or less. Posts are called "tweets," and the action of posting is called "tweeting."

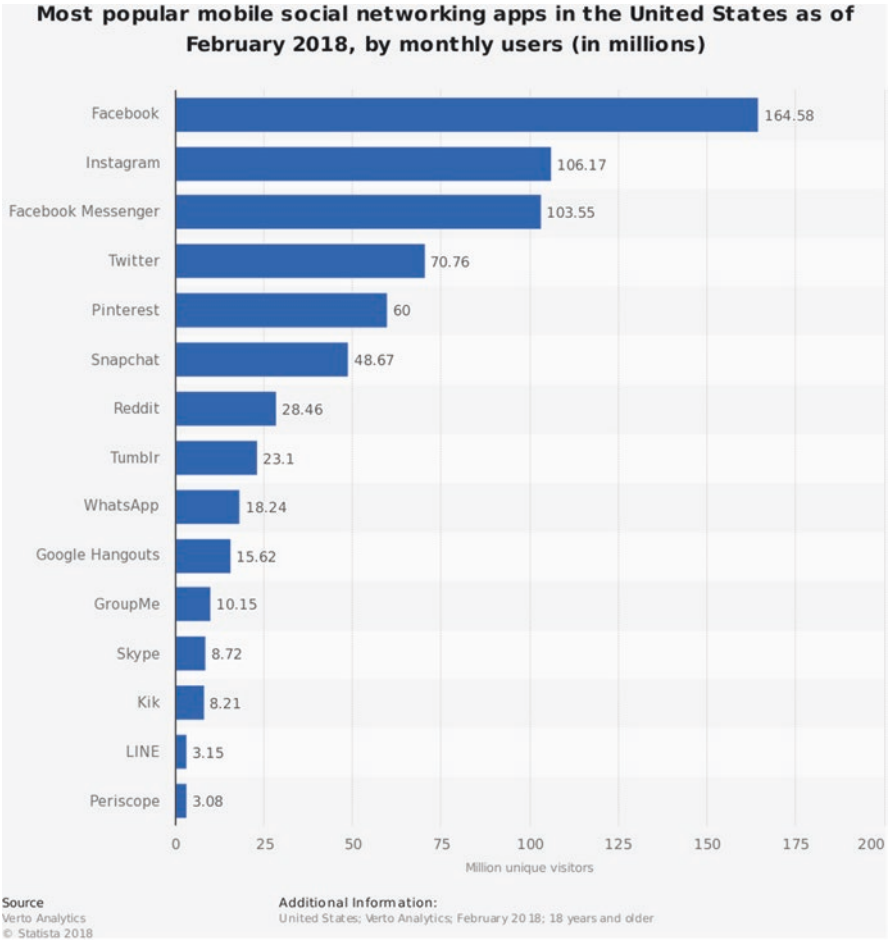

Fig. 4.4 Most popular mobile social networking apps in the USA by visits, February 2018. Source: Statista 2018. Downloaded from https://www.statista.com/statistics/265773/market-share-of-the-most-popular-social-media-websites-in-the-us/. Used with permission

Tweeting is popular. According to research from Omnicore (Aslam, 2017), in 2017, it boasts over 317 million active monthly users, with 100 million active daily users sending over 500 million tweets per day. Although the founders said the initial intent for Twitter use was the sharing of the mundane moments of life, the platform has become a veritable force for information (and, unfortunately, disinformation) delivery. A 2015 survey conducted by the American Press Institute (Tom Rosensteil, 2015) indicated that the most prevalent uses for Twitter involve news (see Fig. 4.5).

Early Twitter users wanted to find ways to group-related tweets, within the content of the tweet, itself. Thus, the hashtag was born in 2007 (Edwards, 2013), to become a content curation and indexing strategy that has permeated cultural consciousness and all other social media platforms. Hashtags link tweets together, and

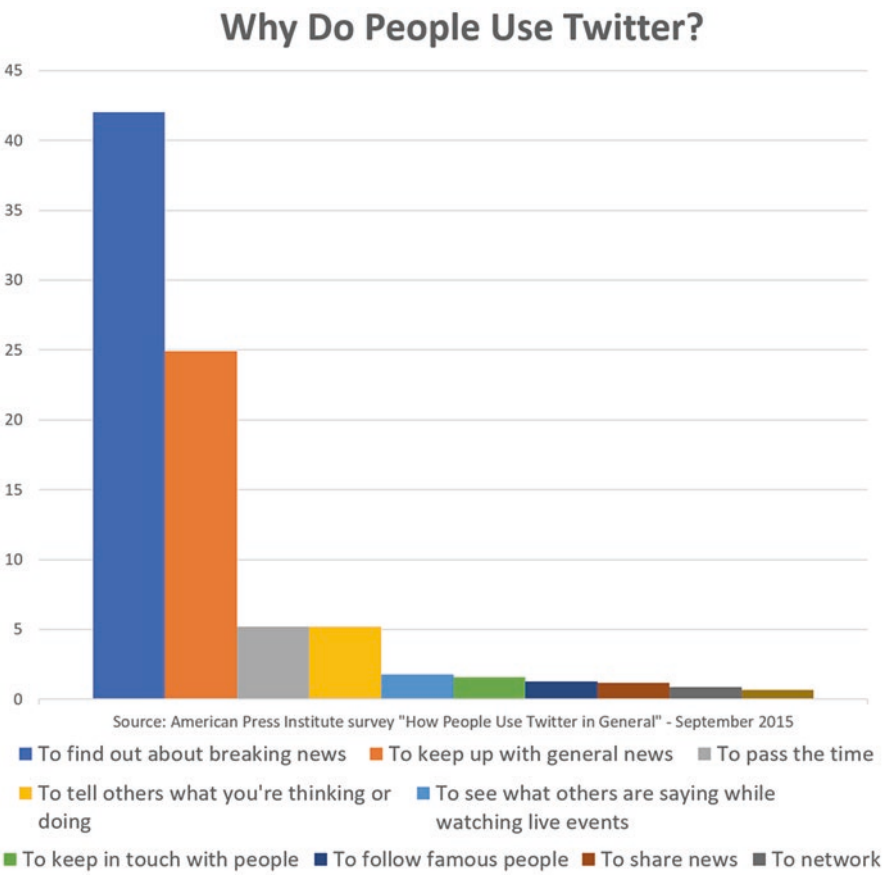

Fig. 4.5 Why people use Twitter, September 2015. Source: American Press Institute. Used with permission

can be used to create communities, targeted topic discussions, and marketing campaigns. Users can search content based on any combination of hashtags, keywords, profile handle, content type (image, link, etc.); these query parameters can also be used to create lists to curate targeted content automatically (see Table 4.1; Figs. 4.6 and 4.7).

Twitter has become a uniquely rich environment for healthcare information seekers and sharers, with hashtag themes connecting individuals across the globe of all walks of life—leveling the playing field between physician and patient, policymaker and constituent. It spawned a dedicated research platform, Symplur (2017), that curates public user-provided hashtags and archives related content so that citizen scientists and academic researchers, alike, can analyze tweet and user profile text in addition to complex network connection patterns between users and topics.

Table 4.1 Healthcare hashtag reference guide

Healthcare hashtag	Description
#HCSM	Healthcare social media
#HITsm	Health IT social media
#MedEd	Medical education
#FOAMed	Free open access medical education
#BCSM	Breast cancer social media
#LCSM	Lung cancer social media
#SPSM	Suicide prevention social media
#Migraine	Migraine community support
#ChildhoodCancer	Childhood cancer community support
#HCLDR	Healthcare Leaders community
#MentalHealth	Topics related to mental health
#SDOH	Topics related to social determinants of health
#DigitalHealth	Topics related to health apps, wearables, remote monitoring, VR/AR
#ED	Topics related to eating disorders—and not necessarily related to overcoming them

Source: Original table created by author

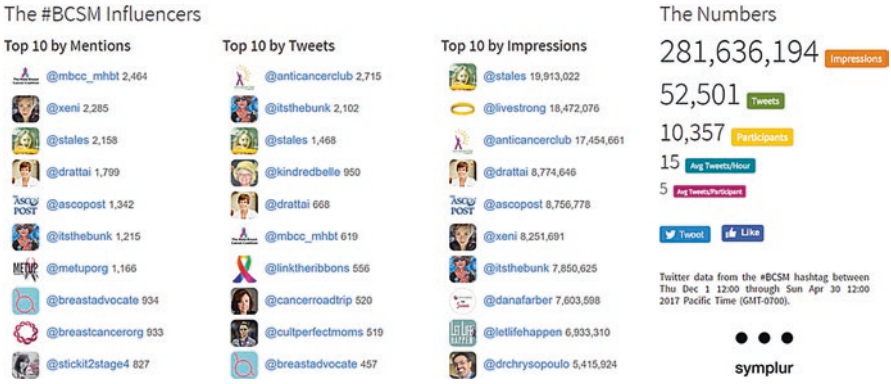

Fig. 4.6 Influence of #BCSM on Twitter-10,300+ Participants, 52,500+ tweets over 5 month period December 2016–April 2017. Source: Symplur Signals, a healthcare social media analytics platform. Used by permission

Blogs

One of the most popular social media constructs that does not fall under the typical platform definition is the "blog," a term coined in 1999 by Peter Merholz (peterme.com, 2002) as a shortened form of the term "weblog." Blogging become one of the most popular forms of content-sharing and engagement on the internet, with more than 180 million individual blog sites in existence.

Fig. 4.7 Influence of #Diabetes hashtag on Twitter-30K+ participants, 112K+ tweets over 30-day period in April 2017. Source: Symplur Signals, a healthcare social media analytics platform. Used by permission

According to W3Techs Web Technology Surveys data from April 2017, more than 25% of all websites on the internet are powered by WordPress (W3Techs, 2017), a content management system introduced in 2003 that quickly became the market-leading blogging platform. Popular with website developers and consumers alike for their extensible architecture and low cost, competing content management systems have proliferated, and with them, the popularity of blogs has exploded.

WordPress, the market leader in blog content creation and viewership, now boasts more than 400 million people viewing more than 26 billion pages of blog content per month on its platform (WordPress, 2017), with more than 87 million new posts accruing more than 44 million comments.

Regardless of the type of health or healthcare-related information one seeks, there is a blog dedicated to the topic (see Table 4.2). Healthcare bloggers run the gamut from patients and caregivers documenting their experiences navigating the healthcare system to doctors and nurses providing answers to some of the most frequently asked, or uniquely interesting, questions they hear. Internet users can subscribe to blogs, receiving updated content when it becomes available, and can often engage with the blogger and the other readers within the comments section of the individual blog entries.

YouTube and vLogs

When a blog's content primarily consists of videos, it is called a "vlog"—and video is the fastest-growing internet content type. Cisco's, 2016 "Visual Networking Index" whitepaper (Cisco, 2016) forecasts that video traffic will be 82% of all consumer internet traffic by the year 2020, tripling between 2015 and 2020.

Table 4.2 Healthcare blogs for all audiences

Healthcare blog title	Website URL	Target audience
The Health Care Blog	Thehealthcareblog.com	Industry professionals
Healthcare Scene	Healthcarescene.com	Health IT professionals
Blog for a Cure	Blogforacure.com	Cancer patients and caregivers
Bitter-Sweet Diabetes	Bittersweetdiabetes.com	Diabetes patients and caregivers
Blogabetes	Dlife.com/diabetes-blog	Diabetes patients and caregivers
Dr. Oz Blog	Blog.doctoroz.com	Consumers and patients
Medscape	Medscape.com	Industry professionals
Dr. Phil Blog	Community.drphil.com	Consumers and patients
Life as a Healthcare CIO	Geekdoctor.blogspot.com	Industry professionals
Health Populi	Healthpopuli.com	Industry professionals, activated patients
e-Patient Blog	e-patients.net	Patients, caregivers, and industry professionals
Caring Bridge	Caringbridge.com	Patients, caregivers
The Hurt Blogger	Thehurtblogger.com	Autoimmune disorder patients, caregivers
The Doc Smitty	Checkupnewsroom.com/thedocsmitty/	Parents of pediatric patients
Kevin, MD	Kevinmd.com/blog/	Professionals, consumers and patients
Dr. Jen Gunter	Drjengunter.wordpress.com	Consumers and patients of OBGYN
e-Patient Dave	epatientdave.com/blog/	Consumers and patients, professionals

Original table created by author

While other social media platforms like Facebook, Twitter, and Instagram have introduced support for pre-recorded and live streaming video, the market leading user-generated video platforms is YouTube, a Google property which, according to the website's most recent published statistics (YouTube, 2018), has over one billion users and reaches more 18- to 49-year-old consumers than any cable network in the USA—as well as reaching exponentially more than any other online video platform, according to comScore's, 2017 Desktop and Mobile Video Rankings (comScore, 2017).

Video is a powerful tool for sharing and consuming information, with individual or corporate vloggers—as well as entire channels of related vlogs—providing content from personal diary-style entries to short films designed to advertise a brand or product launch. One of the most popular video content types is the "how to" video, with 2015 statistics supplied by Google and aggregated in a study by Search Engine Land (Gesenhues, 2015) stating that searches for "how to" videos are growing 70% year over year, representing more than 100 million hours of YouTube viewing annually.

For healthcare, this equates to users being presented with video tutorials on such topics as, "how to complete a Medicaid application," "how to appeal a health insurance decision," or "how to calm a crying baby" (Hamilton, 2015). The latter example represents a vlog entry demonstrating an infant holding technique from a

Fig. 4.8 "I Am A Patient and I Need to Be Heard" Morgan Gleason vlog, January 2014. Used by permission

pediatrician, Dr. Robert C. Hamilton, that "went viral," receiving more than 23 million views in less than 18 months.

Patient stories captured on video can resonate far, as well. In January of 2014, Morgan Gleason was a 15-year-old hospital patient who was fed up with the lack of respect for rest that her care team exhibited. She recorded a short vlog entry (Gleason, 2014) decrying the constant wake-ups, reiterating the phrase, "I am a patient; I need to be heard," and uploaded it to YouTube (see Fig. 4.8).

The video went viral and received national media attention, including an article in Forbes (deBronkhart, 2014) and numerous healthcare industry speaking engagements. With the support of her mother, CareSync executive Amy Gleason, she was encouraged to share her experience with healthcare executives—and the online world—and her story became a rallying cry for patient empowerment.

Yelp and Local Business Review Sites

In addition to blogs and vlogs, user-generated social media content contributing to healthcare consumer decisions increasingly includes ranking sites such as Yelp, which allows users to search for and review local businesses (see Figs. 4.9 and

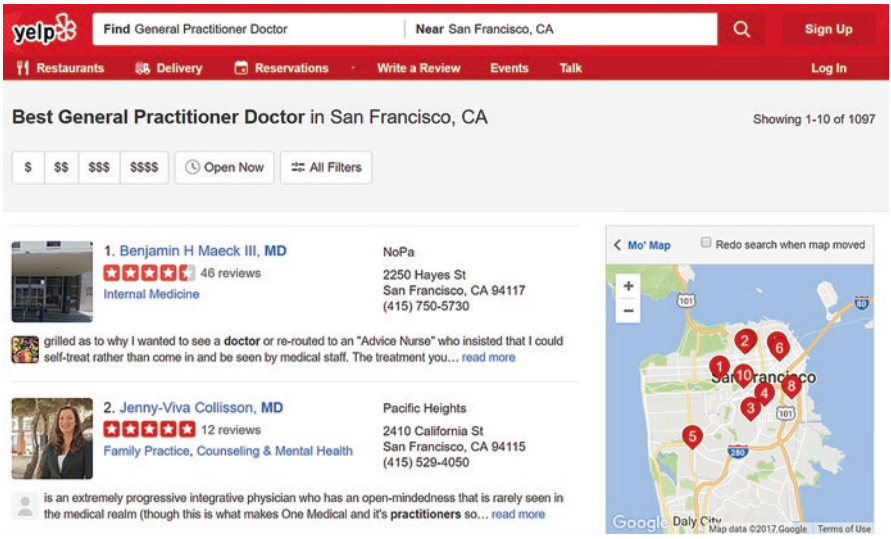

Fig. 4.9 Yelp results for "General Practitioner Doctor" near San Francisco, CA, April 2017. Used by permission

4.10). Leveraging your device's location services, Yelp responds to inquiries regarding "what's near me," encouraging users to "check in" then rate and review the businesses once visited.

As of December 2017, according to its published statistics (Yelp, 2017), the service boasted 73 million unique average monthly visitors accessing the site via desktop, with 24 million monthly mobile app unique visitors, contributing a cumulative total of over 121 million reviews. Although health-related businesses only comprised 7% of Yelp's businesses reviewed in 2017, as the healthcare industry increases its adoption of omnichannel communications and social media that number can be expected to substantially increase.

Yelp, and similar sites like Angie's List, provides familiar ranking criteria—such as stars—as well as user-submitted reviews (and, often, the business responses to reviews). In addition to the specialized business review sites and apps, the most heavily trafficked review and rankings are now aggregated and curated by more general giants, using proprietary weighting criteria, and presented to users searching for a particular business or type of business: Google and Facebook.

As more than 70% of all internet searches are performed by Google, according to NetMarketShare's, 2017 Search Engine Share report (NetMarketshare, 2017), the business star ranking is now prominently displayed on search results (see Fig. 4.10), and Facebook reviews are integrated into Google's local pages, the likelihood that an online healthcare consumer will see a company equated with a stars ranking is very high.

Consumer reviews of healthcare service providers are aligned to patients and caregiver requirements; the types of information provided by Yelp are vastly differ-

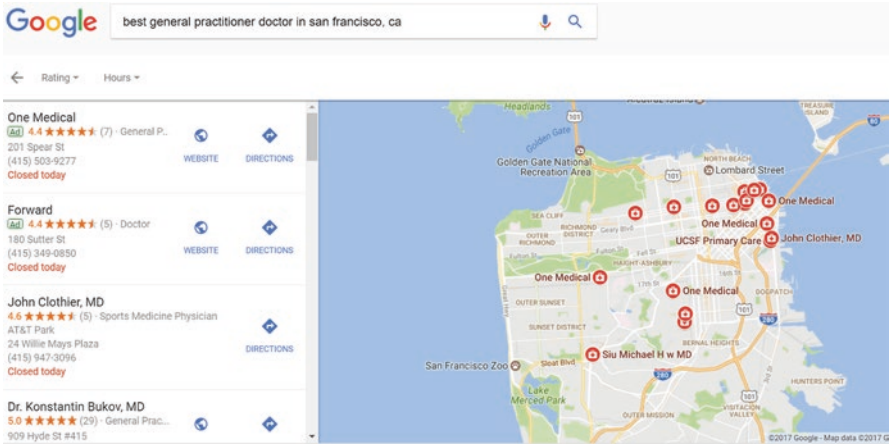

Fig. 4.10 Google results for "Best General Practitioner Doctor in San Francisco, CA," April 2017. Source: Google and the Google logo are registered trademarks of Google, Inc., and are used with permission

ent than that provided by the results of traditional patient satisfaction surveys, such as those routinely collected from Medicare patients. When searching Yelp for healthcare providers, users frequently see comments pertaining to bedside manner, patient's perception of the doctor's knowledge, and the patient's satisfaction with the results (Miller, 2017a, 2017b).

Unlike some social media platforms, blog sites, or online communities, the user-generated content isn't automatically available for others to read and isn't moderated by a human administrator: Yelp purports to leverage proprietary algorithms to determine which reviews to display in what order, weighting frequent reviewers as more reliable and reducing the number of "fake" postings.

Community Websites and Networks

Websites dedicated to health and healthcare-related causes and industries that include social engagement features such as discussion forums and private messaging have proliferated across the internet since the earliest days of public dial-up access. These resources may have blog and content curation components, but their primary focus is community development and member collaboration.

One of the most widely recognized examples of this type of social media network is *PatientsLikeMe*, which launched its first online community for ALS patients in 2006 (Wikipedia, 2017a, 2017b) and eventually has become the largest online population of ALS members in the world. PatientsLikeMe now provides support for

over 2800 conditions (http://news.patientslikeme.com/about/background), and the community's cooperation with researchers and clinicians has led to changes in how the community members' conditions are reported and measured, such as the development of the MS Rating Scale to determine how MS is progressing over time (Wicks, Vaughan, & Massagli, 2013).

Another growing online community is the Society for Participatory Medicine, a membership organization that promotes shared decision-making between patients and providers and supports SPM Connect, a collaboration platform for member discussions about participatory medicine.

Healthcare Social Media Audiences and Use

While there are distinct user roles for those engaging in social media for health and healthcare, there is substantial overlap and fluidity between roles as a user engages, especially among individuals participating organically in social media as a human and not as a brand (see Fig. 4.11). In this context, for individuals, the role assignment is reliably applicable to a single engagement, only; the role represented may change over the course of a series of engagements. Brand personas are less complex, although the individuals engaging on behalf of the brand are often challenged to follow the constraints of role-appropriate representation. Healthcare's social media audiences include: consumers, patients, caregivers, providers, insurers, and researchers.

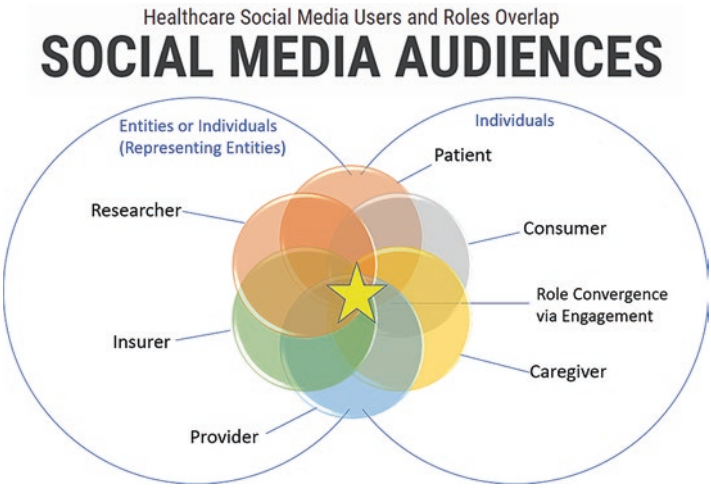

Fig. 4.11 Healthcare social media audiences. Source: Original graphic created by author

Patients and Caregivers

Patients and caregivers are individuals engaging in social media networks for information regarding the diagnosis, prognosis, treatment plan, and impacts of health conditions. Their roles are closely related, and their engagement behaviors are similar. A patient is the individual experiencing the health condition, and a caregiver is the person caring for the individual experiencing the condition. These roles are not mutually exclusive: a patient can be a caregiver to another individual, or to herself.

Patients and caregivers are also consumers of healthcare services; however, interactions as consumers follow a different pattern. To paraphrase Jeff Margolis, CEO of Welltok (Jayanthi, 2015), in an interview with "Beckers Hospital Review" in 2015: consumers make choices while patients receive care.

To extend that definition to address how patients engage in social media: patients, and their caregivers, seek information about the diagnosis, treatment, and management of health conditions. Anyone can become a patient at any time: experiencing unfamiliar symptoms accompanied by an inability of her peers to diagnose her illness, a physician may research social media resources for people discussing similar symptoms. A new mother experiencing post-partum depression while nursing her baby may become actively engaged in an online support group. An elderly research scientist caring for his wife who suffers from Alzheimer's finds himself diagnosed with diabetes, and he seeks help from diabetes groups on Facebook in optimizing his self-care regimen to maximize the time and energy required for his caregiver responsibilities.

According to Rock Health's report, "Digital Health Consumer Adoption: 2015" (Wang, 2015), 71% of all adults with internet access use the internet to search for health information. Of those, 40% who search act directly on the information they find. Beyond searching, increasingly, patients are sharing their stories on social media—proffering clinical and deeply personal details about their experience, and those stories serve to inform and educate others dealing with similar circumstances.

This phenomenon of sharing and commiserating within an online community has been of especially high value to those affected by rare diseases, which affect more than 30 million people in the USA, according to CG Life's recent article, "Rare Diseases: The Role of Social Media in Patient Recruitment" (CG Life, n.d.).

The internet removes geographic boundaries, with freely available translation tools enabling multi-lingual conversation, allowing patients and caregivers without peers in physical proximity to benefit from connections worldwide. By leveraging the internet and its social media communities, patients are able to more effectively find clinical trials, find events or specialized support resources, as well as learn and evaluate tips and tricks for managing conditions from others living with it.

Consumers

Frequently, the terms "patient" and "consumer" are used interchangeably when discussing the roles played in the healthcare system. Often, an individual is playing both roles simultaneously. However, there is a distinction: in the role of "consumer,"

an individual is shopping for, buying, and rating products and services received. While clinicians remain trusted information sources, social media "shopping" allows for instant answers and anonymous acceptance or rejection of the results.

Social media-enabled healthcare consumerism is rapidly increasing. An oft-cited 2012 report from PwC, "Social media 'likes' healthcare: From marketing to social business" (Health Research Institute of PwC, 2012), indicated that 42% of all consumers surveyed search for health-related consumer reviews via social media.

Three years later, in 2015, the Rock Health report (Wang, 2015) indicated that 50% of all online consumers search for reviews of doctors or healthcare services (see Fig. 4.12). And, again, 40% of those act on the information immediately.

For healthcare consumers, social media content provides a smorgasbord of decision support material. In addition to the reviews of providers and services, people share pricing information that isn't readily available through any other means. Patients upload bills, letters from providers or insurers, and tell the story of their financial progression along the care continuum.

This transparency and willingness of consumers to share price data online created a cottage consumer informatics industry specialization, with companies like ClearHealthCosts collecting, aggregating, analyzing, and sharing the data with other consumers. Similarly, the public availability of data sets from the Food and Drug Administration as well as the Centers for Medicare and Medicaid Services supercharged the healthcare data journalism and related consumer decision-support initiatives, such as ProPublica's Vital Signs project (Wei, 2017) (see Fig. 4.13).

Providers

Healthcare providers have a unique and complicated relationship with online information sources, including social media networks (see Fig. 4.14). The regulatory environment, in conjunction with many institutions' discomfort with the fact that there is virtually no surefire way to control information flow once it is released on the internet, creates a delicate balancing act for organic social media engagement.

Although a growing number of providers, both individuals and institutions, are becoming active on social media, engagement between a physician and a patient, specifically directing the care of that patient, is still rare. A number of constraints represent barriers to the use of public social media platforms for clinical diagnosis and treatment.

The Health Insurance Portability and Accountability Act (HIPAA) privacy rule (US Department of Health and Human Services, 2003) is the most oft-cited reason why providers should be cautious—if not downright avoid—social media engagement: yet, HIPAA as prohibitive of this type of communication is flawed rationale. Although the HIPAA privacy rule does set standards for handling Protected (sometimes referred to as Personal) Health Information (PHI) (US Department of Health and Human Services, n.d.), and defines penalties for failure to comply, it does not prohibit engagement or limited information-sharing—provided that the patient involved has explicitly given consent.

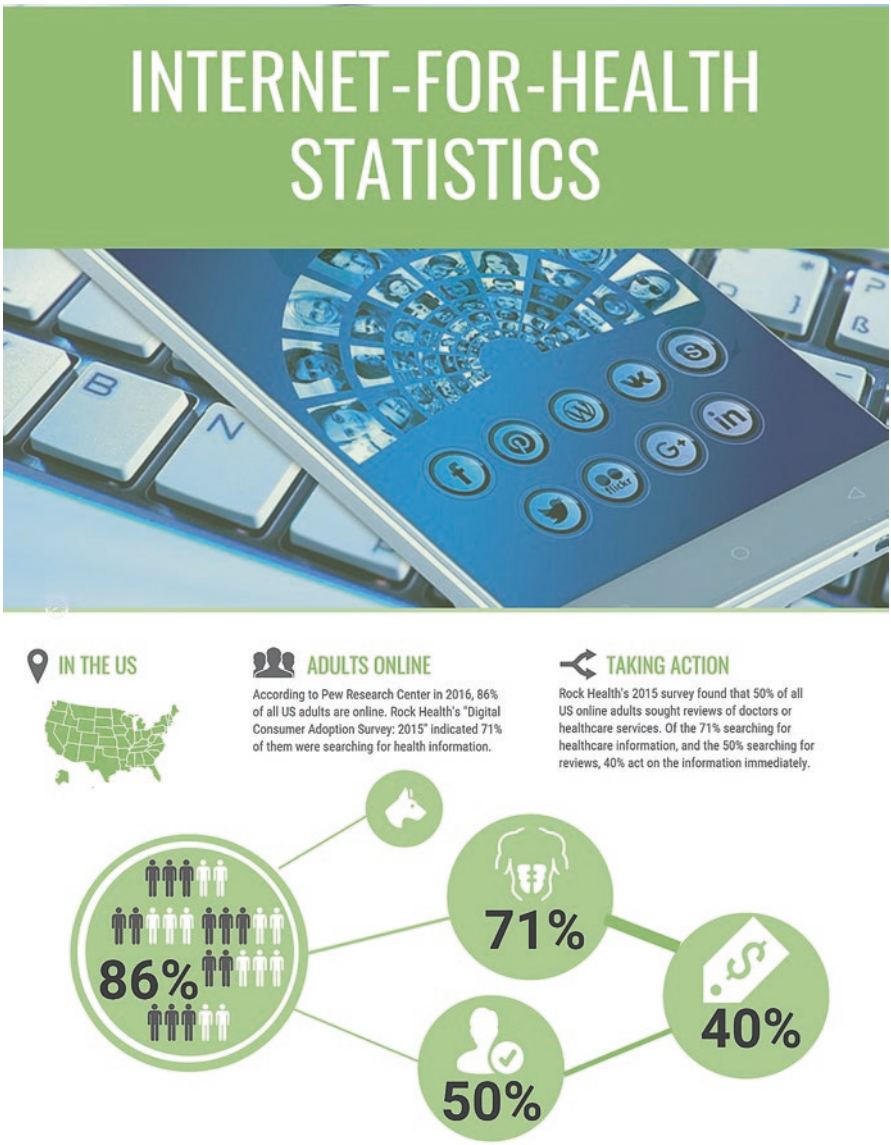

Fig. 4.12 Internet-for-Health Information and Actions Taken Statistics, 2015–2016. Original graphic created by author, based on the following sources: Greenwood et al. (2016) and Rock Health (2015)

Patients and caregivers frequently share detailed condition information on social media networks with the hope that the collective hive-minds of clinicians online may be able to help them better assess and address their health concerns. This information is voluntarily proffered, and frequently leads to expansive conversation about

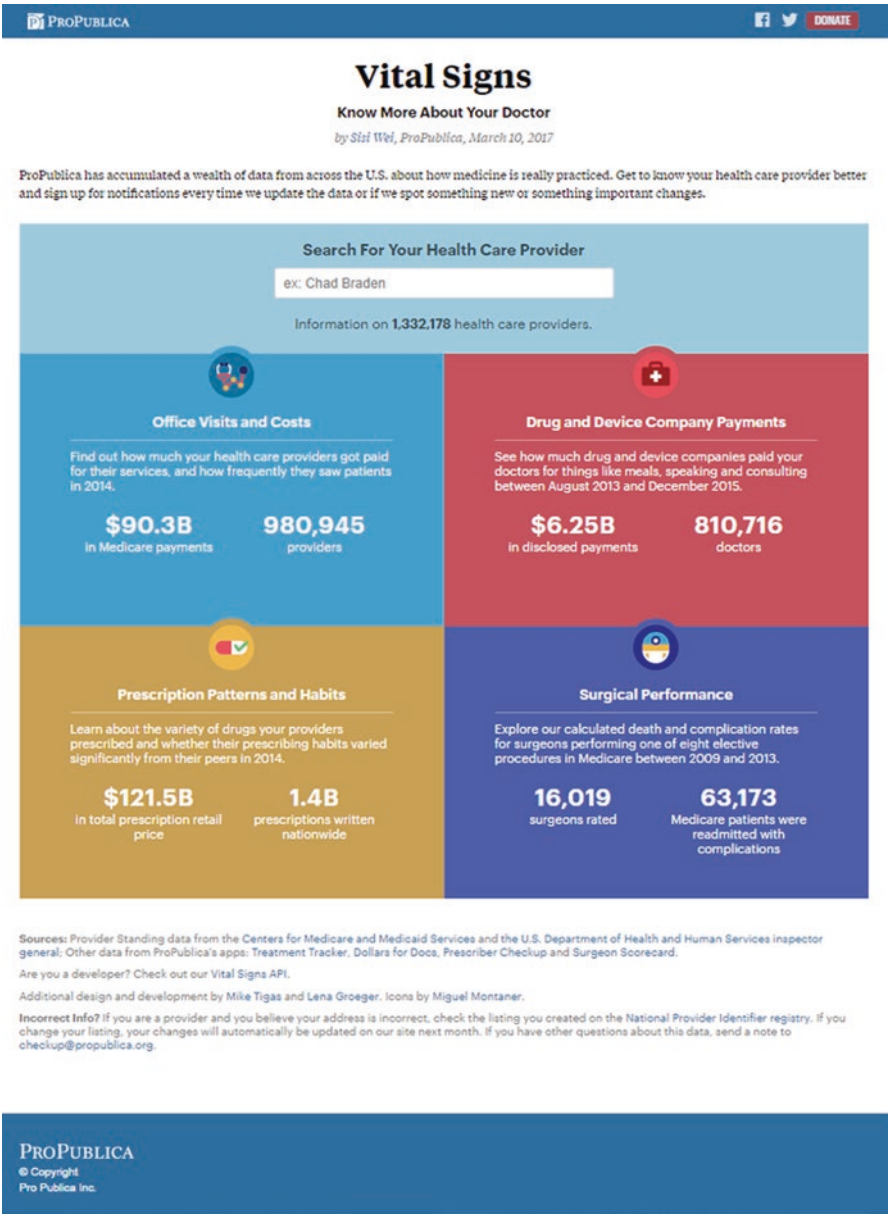

Fig. 4.13 ProPublica vital signs project—cost, quality, and performance data for healthcare consumers. Used courtesy of ProPublica

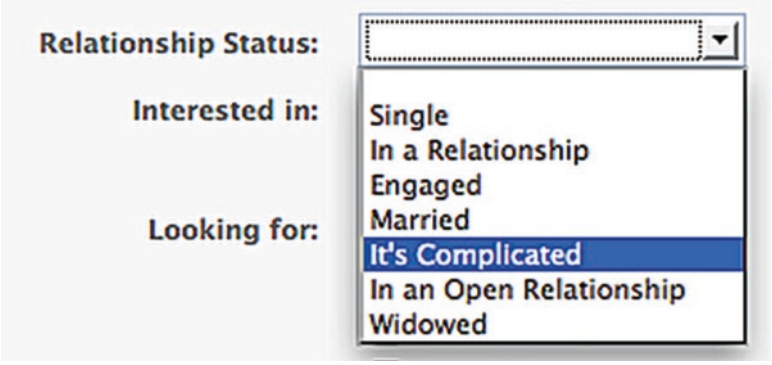

Fig. 4.14 Healthcare providers and social media—relationship status? It's complicated. Source: Meme

diagnosis possibilities, the experiences of others in managing the disease, and clinical research related to the condition and treatment. These interchanges offer valuable insights to provider participants, who have an opportunity to view the patient and caregiver perspective as they navigate the care continuum—and who may learn from the vast experience of the global community of clinicians who engage.

Many providers and institutions are prolific in their online information dissemination, garnering community support and trust through thought leadership and allowing a broad audience to learn from their expertise. Dr. Zubin Damania, the co-founder of the Health 3.0 movement and more commonly known as ZDoggMD (Damania, 2017), creates rap parody videos to make clinical language and healthcare processes accessible. Each video has a hashtag label, so that its pattern of proliferation across social media platforms can be easily captured and studied. One of his most popular, "EHR State of Mind (#LetDoctorsBeDoctors)" (Damania, 2015), gives voice to the pain many clinicians feel with their electronic medical records systems—making the provider experience of being de facto data entry clerks relatable for their peers and the patients they serve.

An institutional provider example of effective provider social media engagement is a video released by Cleveland Clinic, "Empathy: The Human Connection to Patient Care" (Cleveland Clinic, 2013), which showed the hidden stories behind each person encountered in a hospital. It went viral, accumulating more than three million views in a matter of months after release, and receiving thousands of positive accolades in the form of public comments.

Conversely, this effectiveness at social media engagement can also backfire, as evidenced by the public relations firestorm created (Boodman, 2017) when the Medical Director and Chief Operating Officer of the Cleveland Clinic Wellness Institute, Dr. Daniel Neides, posted an anti-vaccination missive (Neides, 2017) on the institution's blog site. Outrage from the medical and patient community swiftly ensued, with widespread media coverage from Forbes (Haelle, 2017) to NBC News (Fox, 2017) addressing the incident available online in a matter of hours from the

post, culminating in Dr. Neides issuing a public apology, and receiving disciplinary action from the institution (Wadman, 2017).

Beyond outreach and education, provider institutions often practice brand protection through social media surveillance (called "listening"), in which online posts are monitored for certain keywords: the name of the organization, an affiliated doctor or place of service, an ad campaign tagline, or other identifying phrase. Positive social feedback can be amplified, and negative sentiments can be addressed, through the strategic application of social media listening and response.

Insurers

Much like providers, health insurance organizations and their employees face a heavily regulated environment with strict compliance standards that must be considered when engaging in social media. Additionally, insurers typically face an uphill trust battle: conventional wisdom is that health insurance is one of the least liked industries in the USA second only to the airline industry. Members don't typically engage with their insurance plan unless there is a health or financial problem, making the relationship dynamic more challenging and adversarial than in a trusted provider/patient scenario.

Yet, there are a number of ways in which savvy insurers are making the most of the opportunities to get social online. One of the most common ways insurers leverage social media is to educate and inform their members and communities on myriad subjects: the benefits that are available with insurance coverage, local health and wellness-related events, clinical thought leadership, and legislative or policy impacts to the marketplace. The content pieces that are distributed on social media can be tracked, so that insurers can better understand how to influence the customer lifecycle and how to produce and disseminate the information items that will most resonate.

Many insurers protect their brand through listening, and some have added the component of timely incident intervention and resolution. Dedicated customer service accounts, often actively monitored 24 h per day, respond instantly to social media posts reporting a specific member's problem: claim or service authorization denial, payment system failures. While few of the insurer's social media accountholders have the authority (or access) to resolve situations, the immediate response and routing to the appropriate channels for resolution is frequently enough to defuse a potential public relations bomb before it can explode.

And explode, it can. As more Americans go online for news and shopping, an inability to adequately provide timely response to or resolve a negative situation that presents on social media networks can result in measurable reputational damage and financial losses. For example, in 2017, Florida Blue, a Blue Cross and Blue Shield network insurer with over four million members, experienced a "glitch" with a third-party payment vendor (Miller, 2017a, 2017b): member bank accounts were debited multiple times, on the same day, for 1 month's premiums.

The uproar from affected members spread across the internet like wildfire, with news organizations reaching effortlessly and immediately into the fray to pluck potential interviewees from the pool of available complainants, while Florida Blue's social media team manning the Twitter handle and Facebook page apologized and urge members to contact the generic email address used for all social media inquiries. An ideal crisis response would have had dedicated and empowered team members managing the communications, and proactively controlling the messaging about the organization's handling of the situation.

Overcoming Healthcare's Objections to Social Media Adoption

As with any type of external communication, there are plenty of pitfalls that healthcare can experience in its journey to widespread social media adoption. However, there are very few that cannot be mitigated, if not entirely dismissed.

"My company doesn't allow it." For some providers, payers, or researchers, in addition to the regulatory constraints previously listed, there may be institutional rules prohibiting the use of social media (although, the number of healthcare organizations who have not, in some way, implemented a social media acceptable use policy to empower their employees and harness influencers is rapidly dwindling). As healthcare consumer decisions continue to become measurably influenced, if not outright made, by social media content, organizations will respond with social media policies and guidelines that will allow, and in many cases encourage, institutional and individual participation.

"I went to medical school. Google did not. I'm not addressing internet diagnoses." Armed with the knowledge that the vast majority of the adult population is online searching for health information, the "Dr. Google" phenomenon is here to stay—and a negative attitude about patients appearing in the office armed with a sheaf of printed websites is not going to change that fact. Instead, ask the patients what social media resources they've used, creating the opportunity to build a library of resources that the practice can verify as valuable (or discredit and educate their patients, accordingly).

"There's no way to validate the information offered on social media." This is a valid concern. An online culture so steeped in fibs that the term "alternative facts" entered the lexicon in 2017 is prone to absorb inaccuracies, if not outright lies. Social media posts do not function like peer-reviewed journals; there is no mandatory verification of the information presented by expert third parties. Old wives' tales and outright falsehoods are commingled indiscriminately with facts, and each audience type is left to their own devices to validate or discount the information presented. However, the fact is that patients and consumers are online, they are engaging with these information sources—and the most significant opportunity to

separate wheat from chaff is to engage, understand the landscape of sources that are resonating with them, and offer truthful variations as necessary.

"I don't want to open myself up to a negative review." Unfortunately, there's no way to prevent this. Doctors, hospital systems, and insurers with the highest quality ratings from government agencies and consumer watchdog groups will experience the occasional negative review. By engaging and building a trusted presence in thought leadership, in addition to continually striving for excellence in service delivery, the positive reviews—and the positive commenters on any negative review received—should outweigh the occasional ding. Negative reviews offer the most growth opportunities, however, and the learning gleaned from them should not be discounted. The grievances expressed on Yelp may mirror issues that will directly impact a health system's patient experience survey ratings for government programs, which would decrease their government reimbursement rate.

"Not everyone uses the internet." This is true. Although internet access, inclusive of all connection speeds, is nearly ubiquitous, high speed internet access, as defined by an internet connection at or equal to 25 megabits per second download and 3 megabits per second upload speeds, is not available to millions of people across the USA. The 2016 Federal Communications Commission Broadband Progress Report (Federal Communications Commission, 2016) found that 10% of all Americans, and 39% of rural Americans, lack access to high speed internet.

Given the rising prevalence of streaming video and image-based content, one's connection speed determines the scope of the social media information available for inquiry or consumption. While blogs and most social media platform content could feasibly be accessible without a broadband internet connection, albeit with limited functionality, resources like YouTube would not.

Additionally, beyond internet access, there is the concern of overall digital readiness for the individual and population served. A 2015 Pew Research Center study on "Digital Readiness Gaps" (Horrigan, 2016) analyzed respondents' comfort and trust with the use of digital tools for learning, and found that 52% of the adults surveyed were "relatively hesitant" to fully adopt digital platforms for education—which serves as an indicator for these personas to engage in social media for healthcare purposes.

Each of these objections is overcome by healthcare organizations every day. None are insurmountable.

Conclusion

We live in an online social world, and the healthcare industry players ignore that at their peril. I am a prime example of the power of consumer informatics via social media: I would not have been invited to write this book chapter if it weren't for my online presence, which allowed my content to proliferate rapidly on a scale not possible without the internet, creating a number of research citations referencing my work in this space, eventually catching the attention of my future editor.

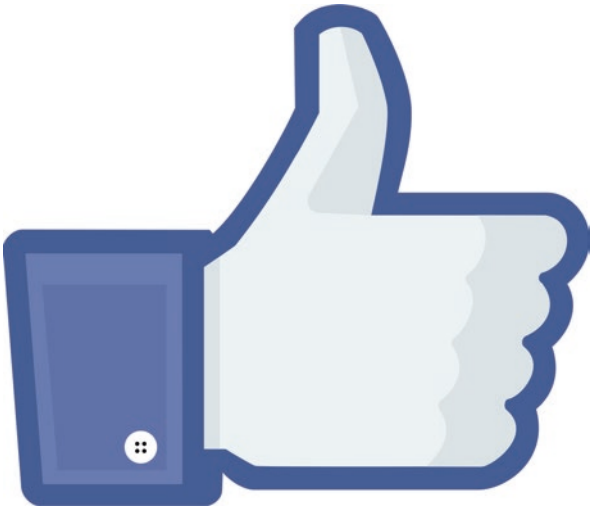

Fig. 4.15 "Like" it or not, social media is democratizing healthcare. Source: Meme

With internet access approaching ubiquity, and social media content-based decision support playing an increasingly large role in our daily lives, the field of consumer informatics—and the healthcare industry—must take the "Likes" and reviews seriously (see Fig. 4.15). Social media is democratizing healthcare, and we, as professionals, must adapt or die.

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Part II
A New Ecosystem for Development and Design

Chapter 5
Understanding Usability and Human-Centered Design Principles

Christopher Hass and Margo Edmunds

Introduction: What Is Usability?

"Usability" isn't a thing, per se, it's a process (www.usability.gov, 2018). And while you may not recognize it for what it is, its absence is painfully obvious. How many times have you tried to enter a building and pulled on a perfectly good door handle only to discover that the door opened with a push, not a pull? Have you attempted to purchase something online and felt lost in an arcane and seemingly malicious checkout process? Read an important sign at an airport or along a roadway that had a font too small to see at speed or encountered an error message so incomprehensible you had to laugh or point it out to someone else?

Conversely, have you ever seen a road-sign and thought to yourself: "Whoever designed that sign made a very astute choice of typeface"? Perhaps, but it's far more likely that you simply used it for what it was: a helpfully placed, designed, and utilized wayfinding tool.

Usable products are often functionally invisible. They enable you to accomplish your intended task with efficiency, ease, and satisfaction. A sharpened pencil can be an astoundingly useful and yet largely invisible tool. If all goes well when using it, your focus is on what you write or draw, not the pencil itself. While we can certainly become attuned to objects we use often, very rarely does one feel the need to stop writing, gaze lovingly at one's pencil and remark "Now THAT is a great pencil!" Yet if the pencil tip breaks frequently, if it is uncomfortable to grip, if the lead is too faint to be read, you can bet the pencil wielder will notice!

C. Hass (✉)
Boston, MA, USA
e-mail: chris@createwww.com

M. Edmunds
AcademyHealth, Washington, DC, USA

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This raises an interesting conundrum: if the most usable objects, products, and services are virtually invisible because they keep your focus on the accomplishment of your intended tasks without disruption, how does one recognize, or better yet, create a usable product? And why do we encounter so many terrible, difficult to use products in our daily lives? Why is it that good design to improve the consumer experience is treated like a luxury or an afterthought?

A common misconception about usability related activities is that they take time and increase production costs. But usability activities, for example, usability tests help to identify problems early in the design process, before software is coded or production has started, and that saves time and money (usability.gov, 2018). Choosing usability or "human-centered design techniques" as a business and process model can contribute to brand value, enhanced utility, safer and more satisfying product and service designs. Healthcare consumers in the digital health market increasingly prefer the brands that take a user-centered design approach. This is true whether they're using a consumer portal to enroll in health insurance (Meier, 2014) or check medical test results, uploading data from a wearable device to an electronic health record (EHR), or using a smartphone app to schedule appointments or refill a prescription. We believe that consumer engagement in health care and health promotion through digital health tools and products will increase as industry and developers pay more attention to design features and usability overall.

How Does a Human-Centered Design Process Work?

Human-centered design processes are surprisingly straightforward to implement. While they must be executed well to be maximally effective, they are highly accessible and intuitive processes that may be undertaken by those who are informally as well as formally trained. Human-centered design professionals, also known as "User Experience" and "Usability" professionals, sit at the crossroads of many fields: engineering, informatics, business strategy, user-needs research, interaction and interface design, visual design, art, academia, marketing, front-end and back-end software development, technical writing, architecture, cognitive science, behavioral science, and many others.

As a multi-sector field, usability and human-centered design entices new practitioners from all professional walks of life because, like the travelers encountering the proverbial elephant, their backgrounds lead them to resonate with a field that elicits value in seeing the bigger picture and enumerating (without bias) the parts individual constituents play in it. (Plus, you can literally fix things that annoy you, and keep new things from annoying others, which can be very satisfying.)

As an interested amateur, through online courses and other resources, and trying out the techniques described below, you can become quite proficient. Simply recognizing a good human-centered design process when you encounter it (or don't encounter it) can be illuminating and offer you opportunities to help guide a product, service, or system to greater efficacy, satisfaction, and/or comfort. If you're a

healthcare professional, this recognition might help you streamline your clinical workflow as well as improve your patients' care experiences. You might even find that fluency with these concepts and terminology leads you to career paths, nuances, and highlights that you never would otherwise have imagined, such as becoming a member of a design team for a health system.

There is a compelling caveat, however. The processes and activities described below are highly accessible and invite (and reward) entry-level experimentation, but when it *really* counts, when lives are on the line, when decisions have significant effects on patient safety, health, well-being, livelihoods, or keeping other mission-critical and highly complex systems in motion, we strongly encourage you to engage experienced experts and human-centered design professionals from human-computer interaction (HCI), human factors (HF), user experience (UX) research, UX design, and related fields of computer science and information science. These professionals' understanding of regulatory environments, ergonomics, human and machine cognition, and complex systems exceeds the value of the specific techniques they employ where the need for certainty, safety, inclusion, scale, and complex systemic efficacy are paramount.

Phases of Human-Centered Design

For instructional purposes, what follows is a robust sample human-centered design phase, outlining activities from product/service idea to execution. Not every activity is required, or warranted, depending on the needs of a given project team. Your experiences will definitely vary, and there are a wide range of activities that could be added in to cover specific situations involving strategic design, behavior change, fostering organizational design thinking, and the like. Please consider this a basic overview of a highly customizable (and interesting) process. For more in-depth information, we suggest Albert and Tullis (2013), Goodman (2012), Mitchell (2007), Rubin and Chisnell (2008), and usability.gov.

Product development typically happens in four phases: discovery, design, development, and iteration. For our purposes, these phases can be described as four major workstreams that have dependencies and often overlap:

- *Discovery Phase*: "Discovery research" refers to any of a series of activities designed to elicit a foundational understanding of a problem space, stakeholder perspectives, project goals, user interaction needs, and user information needs. This includes defining project goals and activity timelines, reviewing prior research, data, and literature, conducting discrete discovery research, and conducting technical discovery. Towards this end, research activities often include techniques such as customer surveys, benchmark usability tests, focus groups, stakeholder interviews, visioning workshops, branding workshops, technical discovery, and any number of "pre-design" activities that contribute to an informational foundation for design decision-making.

- *Content and Interaction Design Phase*: In this product design phase, we use the foundational discovery outcomes of the discovery phase to define a product's content strategy, interaction designs, branding and visual design designs, and then validate those designs by creating screen wireframes, visual design concepts, interactive prototypes, conduct prototype usability testing with core constituencies, and crafting technical documentation (interaction, branding, content, and style guidelines, for example) to support a handoff to the individuals or teams who will implement the final product.
- *Development Phase*: In this phase, the focus is on the development and deployment of the product/service through implementation of its technical architecture, content templates, physical materials, and other forms of instantiation with a focus on accessibility compliance and adherence to relevant regulatory standards.
- *Iteration Phase*: Once a product or service has been deployed, a solid human-centered design system is easily made iterative. Over time, gathering feedback from current and prospective users, analyzing available use analytics, and benchmarking successes against foundational goals are all ways to enable product design and development teams to iterate on the existing designs to fine-tune (or sometimes completely overhaul!) the product. This in effect begins a new "discovery" phase, and the cycle can continue. Products are rarely perfectly designed and deployed, and are always subject to technological boundaries. As such, there's nearly always room for improvement. Fortunately, the same tools are useful the second (or third, or fourth) time around over time.

The application of this systematic approach can have significant benefits. By taking measured steps through the product design and development cycle, individuals and teams are able to assess progress at each step, and more importantly, validate whether they are remaining true to their original goals.

If not, the process supports pivoting: it's far easier to adjust a product's design before you've built it, rather than after. If a prototype reveals itself to be off-target during a usability test series with end-users, then designs can be altered, teams can renew their approach, without having wasted a lot of development hours. In metaphorical terms, human-centered design is very much a "measure twice, cut once" process.

Another interesting facet of a successful human-centered design process is that it attenuates its focus over time in a repeating cycle of activities that offer a "broad" perspective, then "narrow" programmatic decisions towards practical solutions. One helpful way to visualize this process is the "triple diamond" chart below (Fig. 5.1), which is a modification of the popular "double diamond" chart created by the UK Design Council. The Design Council was created by Winston Churchill's government in December 1944 to support the country's transition from wartime to economic recovery (UK Design Council, n.d., https://www.designcouncil.org.uk/about-us/our-history).

Envision a product development cycle beginning at the far left of the chart with an idea for a new or renewed product or service. One day, someone says "What if we did or made X?" It's unbelievably tempting, after having had the idea, to leap directly to implementing it through design and development. And this often happens, which can lead to disconnects between what someone originally thought was a good idea, what the world actually needs, and what ends up on the market.

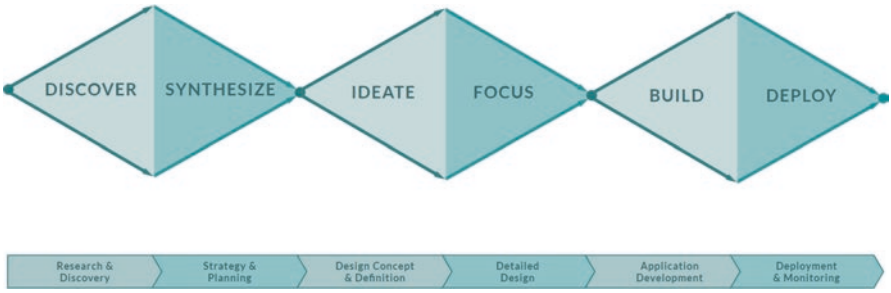

Fig. 5.1 Triple Diamond Design Model (Source: Adapted and redesigned by Mad*Pow and based on Double Diamond Model of Product Definition and Design from UK Design Council, public domain available at https://www.designcouncil.org.uk/news-opinion/design-process-what-double-diamond)

Some systematic checks and balances during the trek from ideation to outcome can be immensely valuable. The "triple diamond" chart shown in Fig. 5.1 indicates this. Starting at the left side of the chart, with "discovery" and moving towards the right side over time towards and through "deployment," then we can see that initial discovery research has as its goal the broad acquisition of a holistic understanding of business goals and end-user information/interaction needs in relation to the product to be designed and engineered.

During the latter half of the discovery phase, we engage in narrowing activities to synthesize research and discovery activity findings down to a manageable set of focused guidelines to support the ideation (or design) phase, which again, starts broad with the generation of a reasonable but wide variety of product concepts which are then winnowed down to a selected approach through traditional design activities: generation of content taxonomies, interaction styles, screen layouts, button/interaction nomenclature, visual designs, and ultimately a documented final design that can be built and deployed.

The building process can be similarly broad, as development activities hone in on the final approach for a successfully deployed product. In combination, this broad-to-narrow to broad cycle is helpful, attenuating the process to ensure that, when implemented well, the overall process is efficient, supports innovation, and provides an effective balance of broad understanding, creative focus, and tactical precision.

At each milestone of the process pictured, particularly at the transition points between "diamonds," a good human-centered design process will feature a validation activity that involves members of the intended product's audiences—for example, a prototype usability test before the design phase is complete, so that the team may verify that their designs adhere to the programmatic goals defined in the discovery phase and that they are usable, accessible, efficient, effective, and satisfying for users to interact with. This ability to periodically validate evolving designs provides helpful insights to product teams—if they are on the right track they may proceed, and if their designs have gone astray, are confusing, or inefficient to use, then they may easily pivot to return to an earlier step.

Benefits of Design Thinking

One of the key benefits of this systematic approach is that it reminds us to be careful not to leap to the design and develop phases too early, and to provide the proper foundational support for creativity and understanding of what will benefit users most. Thus, we can pivot easily without "wasting code," resources, or time, by building first and renovating later. Being able to pivot before committing resources to building helps reduce costs, build clarity around the strengths and opportunities for design enhancement, and helps teams "predict the future" by seeing in advance how users will respond to the product.

This isn't to say that human-centered design practices are timeline-unfriendly or cost-prohibitive. They needn't hamper or hinder a product development process. In fact, they can save incalculable money that might be otherwise devoted to late-stage (or worse, post-deployment) triage if what ends up on the market or in the hands of users doesn't match their needs, isn't easy for them to use, or otherwise fails to offer advantages over what they're currently using.

Often what dictates the scale of a human-centered design process is the need for certainty. If the team needs a general sense that they're on the right track, the feedback of ten or twenty individuals participating in a prototype product usability test may be sufficient. Individual phase activities may take only a few days or weeks to complete. If the team needs a statistical or clinical certainty that a product will do no harm, decrease user error, or otherwise meet intended goals, then research and design activities will likely need to be more robust, requiring more time, personnel, activities, more expertise to execute, and often more funds, to execute.

Overall, a good human-centered design plan involves a close collaboration between product stakeholders, reasonable opportunities for user-needs research to gather observational and interaction-related data from users, and is realistic about available resources, including personnel, time, and budget. All projects are different, but on balance, for purposes of this overview, the phases described above may be generalized across industries.

Product Design Considerations

To be successful, product teams must gain an unbiased understanding of how the users of their product or service work, interweave individual capabilities with institutional goals, know how constituents move through the system, and appreciate what each individual contributor to the whole needs professionally for their work to succeed.

Bringing a product to market and overseeing its installation or implementation is difficult enough to be a kind of miracle on its own. Finding a solution to fit an organization's needs and solve the problems of business, care delivery, public service, and individual employees is difficult in the extreme. Each of the contributors to a

product's design and development are presumably nearly always fully capable, creative, competent individuals. Why then do so many product misfires occur? Why are there so many products in healthcare and other professional realms that are difficult to use?

The answer is frequently very straightforward: those who contribute to product designs often view the execution of those ideas as technological challenges and problems to be solved, and not as human-centered design opportunities. When creating complex products and systems it is difficult to seamlessly dovetail the work of multidisciplinary teams and specialists who are often, by necessity of their specialization working independently on a portion of the whole. In metaphorical terms, undue focus on the "trees" (portions of the whole) can lead to a lack of focus on the "forest" (how the end result will ultimately be used, by whom, and for what purpose). Certainly there may be other contributing factors, but successful product teams ask and answer three basic questions to the best of their ability to begin a human-centered design process.

These questions are:

1. What is the product (or service) for?
2. Who is the product for?
3. What will success look like?

It's possible to blithely toss off answers to these questions (which happens time and time again) as seen in this prototypical Question/Answer example drawn from experience advising clients:

1. Expert: What is the product for? Client response: "Improving care."
2. Expert: Who is the product for? Client response: "Doctors."
3. Expert: What will success look like? Client response: "We recoup our investment costs/we reduce the number of calls to the help desk."

Answers to these questions give crucial insights into their product design processes. Right from the start, the answers can indicate the likelihood of their product's success or failure.

What is the Purpose of the Product?

The first question: what is the product for? is deceptively simple. Peeling it apart may take hours of discussion or extensive research to validate. Someone has had an idea, spotted a need, and sees an advantage to someone (ideally the company AND its customers) in making it a reality.

What organizations often fail to do adequately is validate their ideas by verifying that what they're envisioning (a) solves real-world problems for specific populations, (b) meets a quantifiable and demonstrable need, (c) offers improvement over current ways of doing things, and (d) offers capabilities to key constituents (users) in a manner they may seamlessly adopt—without undue (or perhaps any) training or

re-working of their usual methodology. Successful solutions offer specific benefits that end-users can recognize, utilize, and value as improvements over their existing processes, protocols, and procedures.

In return, adoption of a product contributes positively to the creating organization's bottom line, reputation, market share, and ability to accomplish more. When starting to ask these three key questions, it's not uncommon for a company or organization to realize they themselves don't have a clear view of what they're trying to create, or why. Fortunately, human-centered design techniques offer straightforward mechanisms for helping product teams and their leadership to find their footing and answer these key questions in an effective manner that is both time- and cost-efficient.

Who are the Target Audiences?

The second question: "Who is this for?" typically creates an awkward echo chamber for clients. When a usability professional asks: "Who are your target audiences?" the answers are often institutional shorthand: "doctors," "patients," or "the public." The professional then asks: "What kinds of doctors? Which parts of the public specifically?" The response is often a resolute repetition: "Doctors!" "The general public!" This is valid of course: in the case of public health organizations they do in fact serve the public. But "for everyone" is dangerously vague, even when the audiences are large and diverse.

Saying that a product is intended "for doctors" is usually only a part of the picture. Workflow in a clinical setting is nearly always, in reality, a symphony of interwoven tasks accomplished by a number of individuals across a wide variety of roles. A "doctor" may not in fact ever touch a given website, mobile app, medical device, or other product at all, even though it ostensibly was designed for them. In fact, core audiences might really be nurses, administrators, technicians, or in many cases, medical students and interns working after hours to triage deluges of data gathered during patient encounters.

Knowing who tees up personal health information for review, who gathers medical history data from new patients, who handles patient discharge instructions and care plans, and how each individual contributor to the whole spends their work shift, how information is transmitted at shift changes, and how individuals' work changes throughout their workday (or days) is incredibly instructive.

Early in the career of one of this chapter's co-authors (CH), he had a client who engaged his company to help them redesign a website geared towards providing clinical research-related reporting to clinical care practitioners. He asked his clients who their target audience was. They resolutely and inflexibly responded by saying: "Doctors. Our audience is doctors." As part of the company's website redesign discovery phase, he was to design and host focus groups to foster discussions among their website users about what was working, and what could be improved about their existing website. Suspecting that their audience was likely to be somewhat

broader than the client team would allow, he made a heartfelt pitch for not only having focus groups with "doctors" but some with nurses. With great reluctance, the client allowed him to set up one focus group with nurses, but only on a weekend, on his own time (so it wouldn't disrupt the schedule). They made it perfectly clear that they would be very unlikely to attend the Saturday session.

The first focus group with clinical physicians was on a Friday, with the nurses' group scheduled for the following morning, a Saturday. On Friday, the physicians gathered around the focus group table while the client team observed through a one-way mirror in a usability testing suite. After welcoming the doctors and providing some logistical information about how the focus group would be structured, the conversation went pretty much like this:

CH: Do you use the [client website]?
Doctors: Oh yes! Love it! Couldn't do my work without it! It's amazing!
CH: How often do you visit it?
Doctors: Never been to it. Not once.
CH: How do you get the website content?
Doctors: Oh, my nurses read it, they print off all the information I should have, and they build me a little. .. well. .. print version with just the information I need. It's a great website!

As you can well imagine, it was standing-room-only for the client team on Saturday. They eagerly listened to what the nurses had to say about how they approached the website, which information was most useful to them and to the doctors they reported to, and why. Most informative was the subsequent discussion around how the website might be reorganized to better effect. Without fail, the redesign effort included those recommendations, and others the team was inspired to make, to ensure that information on the website was easy to find, organize, and extract (digitally and through print) for ancillary audiences.

There's simply nothing that compares to the value of clearly identifying who your core audience is, how they interact with your product or service, and what they wish that it provided. The scenario described above has repeated itself time and again throughout CH's career, sometimes in more or less dramatic terms, but without fail, Question #2, and how you work with stakeholders to answer it, has proven to be a powerful one. As the saying goes: "Trust, but verify."

What Will Success Look Like?

Asking an organization's thought leaders to answer the third question, "What will success look like?" is often the most immediately illuminating, as answering it completely invites honesty and provides insight. In response to the question "What will success look like?" it's not uncommon to hear "We want to reduce the number of calls for tech support," or "Clinical teams will stop complaining about the system." With each response to this question from a product team representative, from

business leaders to marketers, to developers, to user experience designers, to trainers and customer-service representatives, there can be new instructive insights into how a department, team, individual, and/or product currently functions (or fails to). The answers also reveal the challenges a new or redesigned product will face during the implementation and adoption phase.

What *specifically* doesn't work for individual stakeholders originates from their sphere of influence and individual point of view. Eliciting those diverse views can be instructive. For a redesign project, ask stakeholders who are involved and those who are overseeing it to state as precisely as they can why they think the current system isn't working for them. In other words, we have to illuminate the challenges of today to envision tomorrow's success.

Here the diversity of stakeholder viewpoints can be really useful. Typical complaints might be things like: "Our consumer portal is outdated and isn't secure," "we're getting too many technical support calls," "the homepage looks old and uninteresting," "our clinicians won't use it," "it's no longer in conformance with new regulatory guidelines," or, more recently: "There's a cheap mobile application out there that does the same thing and looks better than what we have."

Eliciting those insights, and tying them to precise challenges for the evolving idea or product to face (and overcome) helps unify the team's vision and increases the likelihood of their success. Their individual perspectives are very valuable, and being able to bring them together provides foundational support for knowing what success will look like. If each stakeholder is able to articulate the challenges and barriers facing the evolving product, we in effect unify the stakeholders around a common goal and help ensure that their individual perspectives are voiced, codified, and taken into account. This has the net effect of mitigating some (or even all) of the internal divisiveness, or "politics" that organizations can experience.

After interviewing stakeholders separately, for example, it may be useful to draft a "unified vision" document stating, in aggregate, what the lead usability expert or members of the research team have found. It would include an outline of the stakeholders' perspectives as a whole, highlighting where their views of the product/service are aligned, where they differ, and what the group sees as the product's current and future potential, the challenges ahead for it, and what success will look like.

It's important to present this information in a manner that doesn't single out individual stakeholders (ensuring their privacy) and in a manner that draws together their separate views into a non-judgmental whole.

In response, if stakeholders can see their concerns and hopes reflected in strategic and tactical initiatives, and see themselves as part of a whole, the internal politics become easier, they become more willing to accept requirements from other teams as valuable (or more valuable) than their own, and they begin to trust the process. Stakeholders who are organizational thought leaders are going to be better advocates for the overall process, and you're more likely as a strategist, designer, developer, or other contributor to see the bigger picture yourself.

In our view, it's truly amazing to learn how many organizations still move from design to execution without involving end-users in the design process and implementation planning. This failure to engage users heightens risk, can waste time and

money by requiring post-launch redesign and re-engineering (or worse, product abandonment). It also clouds the truths around why a product may not be succeeding (or achieving its potential) by basing business and technical decision-making solely on the somewhat limited data available to companies (e.g., customer feedback, data analytics, sales numbers, for example). Perhaps you'll be able to help break the cycle!

Balancing End-User Needs with Product Stakeholder Perspectives

Within organizations, each team of stakeholders naturally sees the big picture from their own perspective. To an implementation team, a product's key challenge may be one of user perception about its value. To a technical team, the foremost challenge may be a software platform choice or an engineering limitation; to a clinical care team the foremost challenge will be impact on workflow and productivity, and so forth.

To put it bluntly, each member of a team tasked with "redesigning a website," "making a mobile app," "creating a clinical decision support tool," or "designing an emergency response protocol" sees the problem and solution set in a manner informed and biased (for good and for ill) by their own perspective. This isn't bad per se, as it has a certain natural inevitability to it—of course people make decisions based upon their direct experiences—but human-centered design techniques help get stakeholders to pool their knowledge and to understand that the challenge and opportunity of successful product design is to build (most often) a whole creature that is more than the sum of its parts. To meet the needs of stakeholders by drawing upon their collective expertise, it is important to not let the process be overly biased by one or two compelling, often very powerful senior stakeholders operating from a solitary perspective.

In order to achieve this equity in perspectives, it is vital to a human-centered design process to be able to contrast, balance, and dovetail end-user needs with those of the product stakeholders. "End user" is the industry term for "whomever is intended to use the thing you're designing and building." End-users might be consumers, another health system, or persons within your own organization. The key is to design a product, service, or system that meets the needs of whomever is intended to use it, and the needs of the business creating it.

A crucial component of the human-centered design process is not only to ensure that stakeholders are on the same page (and if they're not, to sort that out before diving into design and development processes), but also to provide a counterpoint to the stakeholders' vision by providing a unified end-user vision. By having both, we can compare business and end-user needs and see how aligned they are. This gives us important insights not only into what a successful product/service might look like, but how likely the organization is to offer something useful for end-users. As

human-centered design practitioners we need to be able to say, before entering a design phase, "We know what the business wants, and why," AND "We know what the end-users experience today, what information they value, what their workflows are like, and what might be ideal for them."

We accomplish this by seeking out the end-users' perspectives. We observe them going about relevant aspects of their work or daily life, interview them about their work, we ask them to demonstrate how they utilize relevant tools in the execution of their duties, and we do so in a manner that seeks to avoid bias and to garner insights into both what they do today, and what "ideal" products and services would better meet their needs.

"Ideal" in this context sounds a bit magical, but discussing an "ideal" solution often results in the identification of common use barriers and frustrations. This fosters design team innovation. Learning what is of interest early in the product design phase may dramatically shift an organization's view of what its product should be.

User Research

Research tools for garnering user-needs are varied and ever evolving, but they are well established in several fields, including marketing research, polling, behavioral science, and communications (e.g., Berger, 2016). Some mainstays of research activity include: focus groups, individual interviews, contextual inquiries (where someone demonstrates a process or workflow), direct observation, benchmark usability testing (where someone performs representative tasks with a product/service for the purposes of identifying the product's strengths and weaknesses while being observed), surveys, automated usability testing, data analytics reviews, and customer-service data reviews, among others. In sum, user-needs research is effective when it grants you an unbiased view of how products and services are used, what functional successes those enjoy today, and what a better version would act like in the future.

Similar to the way we turn individual stakeholder interviews into a summary of unified stakeholder vision document (which can be as little as 2–5 pages of succinct aggregated text), generating a unified user-needs vision statement is valuable for comparison with the stakeholders' vision. Regardless of the user-needs research technique we utilize (i.e., in the example above, a focus group series), we analyze the data we've captured and generate a summary findings document that provides a user-centered context.

Next, we dovetail the two visions providing a single document that compares the business goals and the end-user goals. If they are wholly aligned, it's fantastic. If not, which is most often the case, the project and product stakeholders may discuss why their vision is not aligned with the potential information (or interaction) needs of their constituents.

Again, discovering a misalignment up-front, quickly (stakeholder research can be accomplished in a few days or a week or two, and end-user research can be simi-

larly swift), can save a company a lot of design effort and development time working on the wrong things. This process also lays the groundwork for a deeper understanding among the product team that end-user input is valuable, that human-centered design processes are observable and transparent, and that the inclusion of self-validating steps in the product/service design process is helpful. We use the term "self-validating" because by creating a unified vision, stakeholders can come to agreement ("this is what we want to do and why") and by seeing the end-user perspective ("Oh, we may need to adjust our approach") helps ensure that their efforts stay on track to provide something their constituents will find invaluable.

In sum, if stakeholders' and end-users' visions are aligned, we've validated their organization's intentions. If they are misaligned, we've validated the need for further study, further discussion, or perhaps the need for a better product/service idea.

We mentioned earlier that the best products and services are often invisible: simple, artful, enabling users to accomplish tasks without thinking about them too much.

Yet for all their simplicity, product successes are rare enough that we know them when we encounter them (consciously or unconsciously). How? Because we use them. When a tool, website, mobile application, product, or service just works, it's satisfying! When you move through a process you predicted would be a potentially difficult process with ease and you shake your head a little and say: "Wow, that was easier than I thought it would be!" Or you're able to utilize something with efficiency, efficacy, and satisfaction, that's a well-designed tool.

By helping an organization or individual to ask those three questions, we quickly and cost-effectively can help ensure overall transparency (bringing individual perspectives to the fore), foster collaboration (the inclusion of end-user perspectives helps eliminate cross-team friction by providing "impartial" data), and, most importantly, begin right from the start to lay the foundations for a user-centered design and development process.

Who and What Defines Success in Health IT?

The International Standards Organization (ISO) defines usability as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" (ISO9241, cited at NIST.gov). The most familiar example of usability in health care lies in the adoption and use of electronic health records (EHRs), which have been a national policy priority for several years (Edmunds, Peddicord, and Frisse, 2017; Trotter & Uhlman, 2013).

As part of the American Recovery and Investment Act of 2009, provisions known as HITECH (Health Information Technology for Economic and Clinical Health) included financial incentives to encourage the adoption of EHRs by hospitals and clinical practices nationwide, to be accomplished within the decade (e.g., Blumenthal & Tavenner, 2010; Washington, DeSalvo, Mostashari, & Blumenthal, 2017). By 2016, almost all hospitals and 80% of office-based clinical practices had adopted

EHRs in some form, and 9 out of 10 consumers could access at least some of their health information electronically from their providers (Henry et al., 2017).

But that is not to say that EHRs and consumer tools are known for their usability. In 2013, a multi-sector task force on usability convened by the American Medical Informatics Association (AMIA) recommended that the EHR industry conduct formal usability testing on EHR functionalities for a select set of measures that are highly relevant for patient safety (Middleton et al., 2013), due to concerns about the unintended consequences of poor design (e.g., medication errors).

In fact, high levels of frustration have been reported among clinicians about the poor usability of most EHRs, even when they have been customized for a particular institution (Washington et al., 2017). The American Medical Association has also drawn a connection between EHRs and increasing levels of physician burnout and dissatisfaction with clinical practice (Slabodkin, 2018), and evidence about the patient safety consequences of poor EHR design continues to grow (Howe et al., 2018).

A multi-year federal interagency research program was launched along with HITECH to build a framework to measure the usability of health IT systems, with the National Institute of Standards and Technology (NIST) in the Department of Commerce, the Office of the National Coordinator for Health IT (ONC), and the Agency for Healthcare Research and Quality (AHRQ) participating. The original long-term goal of the collaboration was to create usability standards, and one of the first products was a searchable database of web design and usability guidelines. (https://webstandards.hhs.gov/guidelines/). More recently, a "change package" for improving EHR usability (ONC, 2018) has become available.

On the consumer usability side, with a few notable exceptions, such as Kaiser Permanente, the Veterans Health Administration, and Medicare, consumer access through web-based portals is not meeting expectations. Increased attention to usability for consumer technology tools may come from a systematic review using Cochrane Handbook and PRISMA reporting guidelines to identify current practices and promising strategies for user involvement in the development of patient decision aids (Witteman et al., 2015). But at the time this chapter is being written, no clear champion for promoting consumer usability has yet emerged.

Conclusion: The Future of the UX Profession

Human-centered design and UX-related jobs have exploded in recent years. Usability professionals, UX designers, UX developers, and accessibility specialists are in great demand. Exactly why this is happening is anyone's guess, but it makes sense on a very basic level. In our view, there's an inherent value in not only having an idea and making it a reality, but in thinking ahead about how that idea fits into the larger context of its use, how it supports an ecosystem of interactions, and taking specific, measurable steps to ensure that your vision is clear, your idea is sound, and to illuminate the best ways to make that idea a reality.

Who wouldn't want to use their human-centered design superpowers to gain insights into the future—to see how individuals and systems react to your innovations? To use that "sneak peek" into the future to fine-tune your approach? The tireless efforts of HCI and UX educators, industry pioneers, publishers, and practitioners to showcase techniques that have specific, measurable return on investment for improving products and services may simply be paying off, at last.

Where is the industry going? In the time CH has spent as an HCI professional, what was called "usability" (focus on the mechanics of product use) became "user-centered design" (broadened to include the context of product use) which was renamed "human-centered design" (broadened to include not only "users" but systems and product-creating organizations themselves) and tomorrow—who knows—it will likely be called something different.

At its core, at the center of its ever-evolving heart, the human-centered design process is about contextualizing what and how and why we do what we do (use a tool, make a decision, motivate ourselves towards better outcomes, facilitate better outcomes, keep ourselves and others safe), so that we can apply those observations and insights to the products and services we create. In turn, those products and services make local and global sense, as individual pieces within an ever-evolving ecosystem of interrelated capabilities. Human-centered design (HCD) is about taking an unbiased, unflinching look at today to build a better tomorrow—one application at a time.

Because HCD as a field has relatively low barriers to entry, it seems like anyone can self-identify as an expert, which is part of the fun. But that is also part of the challenge as the field grows towards professional certification, as individuals compete for jobs, and as more and more organizations recognize the value that those versed in human-centered design bring to the table.

There are a plethora of online resources for self-study, global and local UX-related professional organizations for networking and professional growth (e.g., User Experience Professionals' Association (UXPA, http://www.uxpa.org), and the Association for Computing Machinery's Special Interest Group for computer-human interaction (ACM SIGCHI, http://sigchi.org). There are also university certification and degree programs (e.g., see Coursera.org), and of course commercial and government organizations (e.g., usability.gov) that value (or need) human-centered design processes to help them maximize the efficacy, efficiency, and satisfaction engendered by the products and services, external and/or internal, they create.

Motivation and behavior change specialists can help programs and organizations understand how best to build tools that improve medicinal adherence, empower and inspire individuals to better safeguard their well-being, and utilize leading-edge understandings of cognition and behavior to foster positive outcomes. Strategy and service design professionals can help organizations take a holistic view of how large scale, complex systems combining automated, non-automated, digital and non-digital components work and may be improved. Accessibility specialists help ensure products are maximally useful for the widest possible populations and use-scenarios.

There also are roles for straight-up researchers, designers, and developers who inform their approaches with insights and empathy for end-users. All are welcome to the table, and they are highly useful upon arrival.

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Chapter 6
A Practical Guide to Usability Testing

Christopher Hass

Introduction and Overview

What Is Usability Testing?

A variety of techniques are commonly used for user experience (UX) research: focus groups, surveys, ethnographic studies, heuristic evaluations (also known as "expert reviews"), cognitive walkthroughs, field observations, and individual interviews among others. One of the most commonly practiced and most powerful UX research tools is a usability test series.

Usability testing is a process and technique mainstay of human-centered design research practices because of its intuitively obvious value and relatively low barriers to entry. Where "quality assurance" testing is often about identifying performance-stopping "bugs," and "market research" is often about understanding the desirability of a product, idea, or service, usability testing is primarily about creating an appropriately structured environment for observing how the human beings intended to interact with a product, service, or system actually do interact with products, services, and systems (or would interact, in the case of prototypes).

Usability tests are research activities undertaken to evaluate the usability of a design, product, or service (*e.g.*, its ease of use, efficacy, efficiency, accessibility, and use satisfaction, among other aspects). The defining component of a usability test is the utilization of a product or service's intended user(s) as the central means of acquiring data through observation of their interactions and the use of post-task interview questions to garner their reactions and recommendations (Rubin & Chisnell, 2008).

C. Hass (✉)
Boston, MA, USA
e-mail: chris@createwww.com

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Usability testing may be extensive, or quite focused. A basic usability test of a website or mobile application, for example, might involve 12–24 users (or fewer) and take a few weeks to set up, a few days to execute, and a week or so to generate findings from. Yet the impact can be disproportionately high, offering boots-on-the-ground insights that can shift a product or even a company's entire approach by providing an unbiased look at how well (or how badly) a product will fare in the hands of its intended audiences.

Usability teams typically involve a nominal number of roles that may be filled by one or more individuals as resources and ability allow. These are most often:

- *Research Planning Lead/Principal Investigator*: A researcher who defines the overall research approach, the participant recruitment screener (usually 10–20 questions asked of potential study participants to qualify/disqualify them for the study), a study flyer (a description of the study for distribution to potential participants), participant consent forms (outlining the study goals, potential risks and benefits for participation, and an opportunity to indicate consent), and the moderator's guide (documenting the study's procedures and metrics and how they are to be used). This researcher is responsible for supervising the study, ensuring participant safety, and leading the post-study data analysis and reporting activities.
- *Participant Recruitment Lead*: A team member or consulting organization that conducts outreach to find, screen, and schedule potential study participants.
- *Usability Test Session Moderator*: A researcher who facilitates usability test sessions with individual participants, assigns participant tasks, ensures the safety and Well-being of the participant, and collects study data.
- *Usability Test Session Notetaker*: A researcher who observes the usability test sessions and captures relevant data including quantitative (measurable) data and qualitative (descriptive) data, often using pre-defined tally sheets and/or a notes-grid spreadsheet.
- *Usability Test Technical Support*: A research team member or associate who sets up and manages any data capture tools, cameras, electronic mixing boards, and the like used to capture sessions via audio, visual, and digital means for later study.
- *Observers*: Any members of an internal or external client team, stakeholders, or members of the extended product design/development teams hoping to gain insights from the usability testing process. To avoid bias, observers are almost never allowed to be in the room with users and session moderators. Most often they observe from behind a one-way mirror, remotely via digital means, or by observing session recordings (or highlight clips) after sessions have concluded.

Usability research teams might be internal to an organization or external consultants brought in as part of a product design or redesign effort. For a given project, a single talented researcher might take all of the aforementioned roles, or work in concert with any number of moderators, notetakers, and technicians collaborating within a single facility, at multiple locations nationally, or internationally.

The most powerful asset a usability research team brings to a product design effort is its ability to garner actionable, tactical, insights through observation of and interactions with target audiences. Yet, despite this unique practical value, it might be surprising to learn that many companies develop products in isolation, choosing to rely on their own institutional or professional understanding of their audiences to guide their efforts instead of baking opportunities for direct observation into their design and development cycles. In the health care field especially, where the usability of consumer-facing tools such as electronic health records, consumer portals, and decision support tools can have serious consequences in terms of quality of life, there is growing interest in improving the patient experience through designing better tools and interfaces (Witteman et al., 2015).

Usability testing is a flexible process that can be formal or informal, formative or summative. When utilized during a product design process to shape a product's design it is said to be "formative" usability testing, and when used to validate a finished (or nearly finished) product's efficacy prior to release it is known as "summative" usability testing or "validation" usability testing. The approachability and relatively low barrier to entry of usability testing as a technique, combined with its very simple basic premise– that observing people interacting with products provides valuable insights that can and should guide product design directions– makes usability testing an exciting and powerful introduction to the human-centered design process.

Those who encounter usability testing for the first time are often happily surprised and highly energized by the precision and clarity that usability testing can bring to a product development cycle and often alter their future approaches to include more formative and summative usability testing. This in turn opens their eyes, and often by extension their organization's eyes, to the practical return on investment that human-centered design and "design thinking" practices can bring to product and service design and development cycles. Usability testing is thus a gateway to human-centered design thinking and practice.

Selection of Settings for Usability Testing

Usability testing can be done informally in offices, conference rooms, cafeterias, and found space with minimal preparation and setup, online through moderated or automated telecommunications sessions, or conducted with great formality and precision in specialized usability testing and observation suites to support clinical trials, medical device design, and/or the design or validation of complex, mission-critical products.

The decision to conduct a lab- or field-based study often depends on a few key factors:

- *Control*: How much can you focus the participants' efforts by eliminating distractions without creating a biasing or "unnatural" use environment?

- *Observability and data capture*: Does a structured lab environment better support the capture of data (audio, video, task-based) and the ability to record or broadcast sessions to observers and/or other members of the research team?
- *Participant access*: How easy/difficult will it be to get participants to come to you? To visit them?
- *Accessibility*: Is your testing facility accessible to persons with disabilities and/or who use assistive technologies to interact with products and services? Are those assistive technologies non-portable, highly customized (in which case providing an un-customized substitute might be problematic), and would participation at your facility represent a safety, privacy, or other type of risk to participants?
- *Environmental Impact*: How important is the participants' "natural" environment, their workplace, their home, to understanding and observing product use?
- *Risk and Oversight*: What, if any safety, privacy, or other risks might participants encounter?
- *Interaction Fidelity*: How faithfully can the intended product or service be used for study purposes? Is it ready to interact with on its own, or will portions of it need to be simulated or otherwise worked around in order for target audiences to get a sense of its intended purpose, organizing principles, and interaction motifs? How "natural" are their interactions able to be?

In the context of usability testing "Natural" behavior is a desirable factor as it offers insights into how the product will fare "in the real world." However, the inherent artificiality of a usability research study works against fostering a "natural" use environment. In structured, formal environments people tend to behave more formally and their comments are often less critical than if they were on their own, unobserved, with no immediate ill-effects from providing negative feedback. For example, in a moderated usability study a participant might truly loathe a website they're being asked to use, but hold back their negative comments about the website for fear of hurting the moderator's feelings, or the feelings of anyone observing the session who might have been involved in creating it.

In addition, because participants are being asked to attempt specific tasks while being observed and often recorded, this can cause emotional discomfort. Ensuring that participants feel comfortable and can reasonably interact in a manner that adequately simulates product use involves both careful planning and skilled moderation. Decisions whether to utilize a lab- or field-based approach often involve determining which environment is appropriately "natural" in relation to the fidelity ("doneness") of the product being tested.

In other words, when deciding whether to conduct a lab- or field-based study, a central concern in all types of usability research is how to create a research scenario where relevant data can be captured in as unbiased a manner as is reasonably possible. The "pros" of conducting a lab-based usability test are generally associated with being able to build in scientific controls to the usability testing process. These include being able to closely observe behavior, to structure and sequence activities,

to limit participant distractions, to set up data capture technologies, and to benefit from utilizing a safe and often observable testing location.

Cons of lab-based usability studies involve the overall artificiality of the testing process itself ("come to my location and use this thing as if you were using it somewhere we weren't observing you"), the practicalities involved with recruiting, scheduling, and hosting study participants, the logistical burden placed on participants who often must travel to the testing lab location, the overall accessibility of your lab, and the setup and maintenance of the space itself.

Field testing also offers similar pros and cons. Pros often include a heightened "naturalness" to the study brought about by engaging with and observing participants in their own work or home environment, gaining a broader view of the product's "use ecosystem" because you're seeing the product use in context, and a greater likelihood of ancillary, ad hoc, findings.

A good example of a common ad hoc finding researchers see in the field that they couldn't see in a lab setting is what happens when, instead of having a clinic administrator visit a usability lab to demonstrate their use of an administration software suite, researchers visit administrators in their clinical settings to conduct the test. More often than not, researchers will find that administrators have placed sticky notes with shorthand information on or around their computer monitors. These notes often contain information the administrators have found useful to have at hand, and they have done so largely because the software they are using failed to aggregate that information and present it in a suitably helpful manner to support their workflow. Seeing those post-it notes in context can provide valuable insights that might guide a design team towards potential new features or interface improvements for the software that could greatly increase user efficiency, user confidence, and offer competitive advantage. Context can beget insights.

For this reason, there is a dedicated technique outside of usability testing called contextual inquiry that involves the direct observation of people and their product use in the field for the purposes of gaining insights into holistic product use environments (Beyer & Holtzblatt, 1998). It's also a good example of the crossover possibilities inherent to many UX research techniques. A researcher who observes sticky-note use while conducting a field-based usability test while administrators use their own software is still conducting a usability test, but gaining a bit of contextual inquiry insight as a bonus. Cool, no? While we want our usability tests to be structured effectively, maximally effective study design, particularly in the usability realm, can involve an inherent flexibility.

Some of the cons of field research can include increased distractions for the participant, a reduced amount of control regarding equipment use for data capture, added logistics for travel and scheduling, and the difficulties of maintaining the participants' attention to the study tasks while immersed in their workspace. A common example of the conundrums associated with field-research arises in relation to observing persons who have frequent on-the-job interruptions, who conduct their work in multiple locations throughout the day, and/or engage in interactions where observing them would violate privacy laws, such as the communication between a patient and their physician. In some cases, extracting a professional from their work

environment to focus solely on the interface or tool you're interested in is advantageous. Additionally, sometimes we need to find analogues for patient–provider communication because direct observation isn't possible or would be difficult to arrange without raising concerns about privacy.

The decision to host a lab- or field-based study often boils down to how important the user's use-context is for engaging with the product to be tested. There are always concessions to be made for practicality, time, budget, team availability, access to participants, and the fidelity of the product to be tested (e.g., idea, prototype, and existing product).

A vital common thread that ties both lab- and field-research together is that a successful usability test will often mix interview opportunities ("tell me how easy or difficult that task was to complete, and why") with observation opportunities where researchers can note discrepancies between what participants say and what they do. This isn't to imply that participants are intentionally disingenuous. As mentioned above, it's difficult to relate how many times I've observed a study participant struggling mightily, painfully, laboriously to complete a task on a badly designed website (for example) yet when asked about their experiences, for them to shrug and respond "It wasn't so bad" just to spare the moderator's feelings, simply to be polite, or because they lack confidence in their own opinions of their experiences.

Skilled usability testing moderators ensure that participants are encouraged to speak freely in a number of ways. Common methods include using the introductory moments of the study to orient the participant to the study's purpose and to state that the goal of their involvement is to uncover what is and isn't helpful about the prototype, product, or service they will be interacting with. Moderators often reinforce this information by adding that they themselves have no inherent stake in the study outcomes, that they themselves did not design the product being evaluated (so long as this is true), and that participants' comments and task ratings will neither hurt, nor bolster, the moderator's feelings. Even having said this, social norms are powerful, and usability testing moderators must closely observe not only what participants say, but their actions, affect, and body language whenever possible in order to provide a well-rounded picture of participants' reactions during a usability test.

It is important to note that this is not in any way because "participants lie" (which is patently untrue) but rather because the general population rarely spends a lot of time thinking about how products are designed and is quick to assume that if something is difficult to use, it's their own fault. This is evidenced by how rapidly usability study participants blame themselves when struggling with a task. When facing interaction difficulty, participants often offer comments akin to: "It's not that bad, I'm just not very tech savvy," "I must not be very smart," or: "It's my fault. I'm sure someone else could do this more easily."

In these instances, usability study moderators are careful to gently re-orient participants when appropriate, towards identifying the aspects of the product that are difficult to use or otherwise failing to support them. After all, if the goal of a product is to be used, and it can't be used easily, effectively, without error, and with satisfaction by its intended users, it won't (or shouldn't) last long on the market. When, and

how, to intervene during a study session to help a participant keep their focus on the product is a fascinating part of the art and science of usability testing.

When study participants blame themselves, it can make participation in the study stressful for them. Above all, a study moderator's job is not only to facilitate usability testing sessions, but to ensure that participants experience no undue stress while participating. Great care goes into the design of usability study sessions to ensure that the overall scenario and tasks are realistic and that as many risks as possible to the participants are predicted, ameliorated, and/or removed.

Predicting and addressing potential risks is a key component of usability study design and the decision to conduct a lab- or field-based study, particularly where medical devices and patient privacy are involved. Beyond safeguarding the emotional well-being of study participants, good research study design protects the physical well-being of participants as well. Study designers think holistically about the participant experience from start to finish: how potential participants will be defined, contacted, screened, engaged, participate (physically and emotionally) in the study, receive an honorarium for participation, and return to their lives easily and safely after participating. In health and medical-related usability testing there may be inherent risks associated with product use.

For example, imagine that you were asked to design a usability study with the goal of evaluating the safety, ergonomics, and instructions associated with removing an insulin injection pen from its packaging and utilizing provided written instructions to assemble it. What risks might you anticipate would be associated with asking participants to handle a prototype injector pen and to use its needle to simulate an injection of saline into an orange (as a stand-in for injecting themselves)? What could go wrong? How might your planning avoid the most dangerous potential outcomes, and how would you prepare for unforeseen eventualities?

Fortunately, when it comes to study design decisions, we as researchers are not alone. Research organizations typically have a defined internal Institutional Review Board (IRB) that is tasked with reviewing potential research approaches before they are put into practice, in order to ensure that research plans are humane, appropriate for their intended purposes, and legally compliant with institutional, industry, state, national, and international regulations and best practices.

Typically researchers document their study design plans and submit them to an IRB to garner their review, comment, and approval. It's not unusual for a research team to go through one or more review rounds with an IRB for the betterment of the study and the safety of the potential participants involved with it. In the event a researcher or research institution doesn't have an in-house IRB they may utilize an external IRB company in the same manner.

Involvement of an IRB will add additional time to the study planning and execution cycle, but IRB input and signoff can be invaluable for ensuring legal and best-practice compliance with research standards and requirements. Anecdotally, IRBs may be more familiar with clinical trial research, and less familiar with usability research's frequently smaller scale and less-stringent norms. As a result, IRB involvement may involve time invested providing the IRB orientation to the goals and standard practices associated with usability studies (involving humans to

evaluate products) which can differ from an IRB's experiences with clinical trials or other forms of "human-subjects research" where the participating human *is* the study focus.

In sum, observing what people do often gives us valuable insights that sometimes contradict what they say. Successful usability study setups offer opportunities for participant feedback and observation of their behavior while minimizing risks and potential harm to participants.

Data Collection

Beyond the selection of a usability testing environment, successful usability studies also are structured in a manner that allows researchers to capture both qualitative data (participant comments and non-numerical feedback) and quantitative data (numerical feedback or data such as task ratings and task completion times) to augment observational data. Capturing both qualitative and quantitative data helps researchers and those who receive the study results to paint a broader picture of a product's successes and challenges. In addition to helping researchers to hone in on key study findings, both "quant" and "qual" (as the industry shorthand refers to them) help others to better understand study outcomes.

Some people respond to stories, others to data. A combination of qualitative data ("People had the following positive things to say about the new design…") and quantitative data (e.g., "Participants were 84% faster at completing core tasks with the new design and committed 7% fewer errors") helps researchers not only to gain more robust insights, but to communicate them meaningfully as well.

While reading this chapter, you may spot me utilizing some linguistic backflips with phrases like "the product to be tested" or "idea, product, or service." This is a necessary gymno-linguistic approach because virtually any product or service may be usability tested as an idea, prototype, process, or actual "thing." Usability testing is not an inherently digital, analog, or physical process. In fact, many of the complex product and service ecosystems in use today (and being designed for tomorrow) feature combinations of online, offline, and real-world interaction and systems support.

Take the oft-used example of a patient and doctor interacting during an annual physical. Imagine that during the physical the doctor prescribes a blood test and informs the patient that another member of the care team will contact them within a few days to schedule the blood test and that the patient will need to visit a different facility for the blood draw. A few days later, the patient receives an email from the care team with a link to an online patient service gateway website. The patient attempts to log in, realizes they have forgotten their password, and spends some time recovering or resetting their password to regain access to the site. Once logged in, they utilize a scheduling tool built into the website to make an appointment.

The website then provides directions to the blood lab, which the patient copies and pastes into an electronic calendar reminder, and prints the directions just in

case. A few days later, a technician working at the blood lab associated with the patient's care team can log into the same system but utilizes a very different looking and acting interface to view the day's schedule of patient visitors, make logistical notes for other members of the team, and to print the day's schedule.

Simultaneously, the patient's care team might log into the same system to see an overview, again, via a very different interface, of which patients have and have not scheduled their prescribed blood draws. A care team administrator might then flag unscheduled patients so that the system can send them reminders via text, email, phone call, or other preferred contact channels.

Planning a Usability Test

In the example above, the multi-variate and connected nature of the notification and scheduling process can bring a symphonic coordination or introduce a cacophony of failure touch-points. If you were planning a usability test of the patient gateway website: Whom would you want to observe? Which interactions would you want to see them engaged in? What data would it be helpful to collect? How much of their time would it be reasonable to ask for? What sort of compensation (honoraria) might we offer as an incentive?

There is no single response to these questions, but a potential response might look like this:

- *Target audiences*:
  - Physicians ordering a blood test.
  - Patients needing to schedule a blood test.
  - Testing facility nurses/administrators responsible for daily patient blood test management.
  - Care team nurses responsible for verifying patient lab-test scheduling and outreach.
- *Interfaces to study*:
  - Patient gateway, the scheduling feature, reminder messages.
  - Physician gateway, blood test ordering feature, patient response overview.
  - Administrative gateway, the schedule reporting feature.
- *Lab study pros*:
  - Focus on the interface without professional or environmental distractions.
  - Likely reduction or removal of access to HIPAA-protected patient data.
- *Lab study cons*:
  - Diminished realism in the scenario.
  - Potential need to generate "generic" patient data not associated with actual patients.

- *Field study pros*:
  - Focus on the real-world use of the gateway website.
- *Field study cons*:
  - Physicians, care providers, admins, highly likely to be distracted and focused on their job, so the study will be more observational than interactive.
  - Potential exposure to private patient data.
  - Patients' response to reminder communiques and website interactions are likely to be similar whether in their own home or the lab.
- *Individual study session length*:
  - 1–1.5 h
  - Welcome, consent form administration, and study orientation (10 min).
  - Pre-task professional background interview questions (10 min).
  - 3–5 Interface tasks (50 min)
  - Post-session interview questions (20 min).

For the purposes of this example, a lab study might be logistically more advantageous, as the benefit of participant focus may outweigh the benefits of a more "natural" testing environment. If both a lab- and field-setting were to be used, it might make sense to have the patients participate in a usability-lab setting, since their home environment may have less bearing on the design of the interface related to them. Conversely, seeing the care team and administrators using their respective interfaces in context (busy, multitasking, incorporating this interface into their workflow alongside other interfaces) might prove highly instructive. However, the logistics, privacy concerns, and risk of interfering with their work might outweigh the benefits, leading the research team to opt to have these audiences also visit the usability lab to benefit from the focus a controlled environment affords.

By having each of these audiences utilize the patient/institution gateway in an observable manner and examining the data collected to generate findings—which interactive interface elements or screen layout choices are causing interaction difficulty, for example—product design and development teams gain specific and direct insights into how individual users interact with complex systems.

Usability testing can provide invaluable data and creativity inspiration as well. Design and technical teams have a natural tendency to fall in love with their own ideas, or to prefer one technical approach over another without fully understanding its ramifications for users. During the design and implementation processes, particular design and development solutions are often selected because they solve the greatest number of known problems with the greatest simplicity. However, it can become easy to miss the forest for the trees. Usability testing offers team members the chance to step back, take a holistic view of how well an idea, product, or service, will fare in the "real world." By observing target audiences struggling to understand a website's layout or parse the meaning of an ambiguous error statement, teams learn not only what isn't working, but gain valuable fuel for their own creativity to

design and implement solutions that work better. Usability testing findings can help user needs become design and development directives and goals.

It's also helpful to note that the addition of end-users to the design and validation process in a structured manner doesn't make the user "a designer" but rather adds their perspective as foundational support for defining product goals and success criteria. (There are collaborative design techniques that involve end-users directly in design activities, but they are generally not a part of a usability testing process.)

It's also important to note that despite its name, "usability testing" is not a process for testing the users themselves. Users are a means to understanding how well (or how badly) a product serves its intended audience. The focus of usability testing is the product or service being designed or validated. Usability test studies involve humans but they are not tests with human-subjects. This is a key distinction.

Selecting Audiences and Recruiting Study Participants

As a process, usability testing starts well before a study participant sets foot in a usability lab. Among the earliest tasks in the usability test series planning process are to define a study description, develop a recruitment screener, and develop a consent form.

In order to do this, teams ask and answer the questions: "Who is intended to use this product?" "How will we describe our product and who we are looking for to test it?" and "What risks are associated with participating in our study?" Honing in on a manageable number of audiences, and being unbiased in their selection, can be difficult. As discussed in other chapters within this book, particularly in a care delivery setting, product teams have a tendency to think broadly. "This product is for everyone," or "it's for doctors to use" are common examples. In particular, "doctors" is an oft-used shorthand to describe a wide range of roles and responsibilities associated with product use from physicians, to nurses, to administrators in all their various combinations and diversities.

Discussions to define "core" or "key" audiences can be time consuming, but they are well worth the investment in order to define a reasonable and fair summary description of ideal participants. The same goes for a study description, or "flyer" to be used to support the recruitment activities. A study flyer is the outreach message distributed to inform potential participants about the study and instruct them as to how they might participate. Flyers typically contain a concise overview of the study with a description of whom the research team would like to participate in it, a mention of participation honoraria, and contact information for recruitment purposes.

For example, a mobile application usability test flyer might include the following: "Do you use Application X? We are seeking people who work in long-term care facilities and have used Application X professionally for at least six months to participate in a 1-h study. Parking expenses and a $100 honorarium will be provided. If you are interested call or email…" This message might be distributed electronically,

posted to social media outlets, used by a professional recruiting firm, sent to current or potential customers, or distributed on literal fliers posted in relevant locations.

The key to writing a good flyer is to keep the description broad enough to invite response, but narrow enough to ensure that only persons who might reasonably qualify will respond. Once potential participants begin responding, they are asked the recruitment screener questions, or "screened" to see if they are appropriate for participation in the study.

At its simplest, a good recruitment screener is a reasonably sized set of questions posed to potential study participants to qualify or disqualify them for participation in a study. Successful recruitment screener questions must accurately differentiate between participants and non-participants in a manner that does not unfairly discriminate against individuals. When an appropriate number of respondents have been screened and scheduled for participation, the research planning team declares the recruit closed and proceeds to get ready for the participants' individual sessions.

A recruit seeking a generalized audience typically takes 2–3 weeks after the recruiting efforts begin to secure 10–20 participants, but there can be a lot of variability in this timeline. Specialized audiences, such as persons with specific medical conditions or unique professional backgrounds, can require a more hard-target search, larger honoraria as compensation, and/or more time to locate. Engagement with professional recruitment agencies can be helpful and they often work closely with UX researchers to predict costs, potential recruitment hurdles, and to otherwise support recruiting efforts.

Informed Consent and Honoraria

A key document associated with participant recruitment is a consent form. A consent form is a paper or online document outlining the parameters of study participation. It also describes any risks associated with participation; how the study designers have addressed those risks; what sorts of data will be collected; who will have access to it; who is in charge of the study; how that person or persons may be reached; whether or not they can share their study experiences with others; and an opportunity for indicating their consent if they understand and are in agreement with the information provided.

Due to the importance of communicating this information and ensuring that participants are able to understand it, successful consent forms utilize "natural language," meaning that even though they can be considered a legal document they feature straightforward phrasing that makes interpreting study participation ramifications clear (see Hermosilla, 2015; Jones, 2010; Redish, 2012; Wilbanks & Holve, 2015).

In the case of a typical lab-based usability test scenario, the consent form outlines the parameters of the usability test scenario, the typical length of sessions, the study's purpose, and most importantly, participants' rights. These often include

participants' ability to initiate a rest from study activities or to stop the session at any time for any reason. The form further informs them that their participation in the study will be recorded (audio and video) and that the recordings will be used solely by the research study team and will not be made public or identify participants personally to anyone outside of the research team, not even the clients funding the study. Participants' comments and those of others participating in the study will be anonymized to safeguard their identity.

The consent form further states that an honorarium will be provided for making a good-faith effort to participate in the study. Honoraria, mentioned above, are payments given in return for a service (in this case participation in a usability testing study) for which otherwise a price could not be charged either by law, propriety, or custom. In other words, the study host is ideally providing reasonable compensation for participants' involvement in the study.

It is legally permissible to provide remuneration to study participants for the time they invest in participating in a study. There are, however, important subtleties to the laws and best practices that guide US-based research studies and the provision of honoraria to research study participants. User experience research studies by law and accepted practice cannot coerce individuals to participate in a study, nor can they "pay for performance." By undergoing the study recruitment process, being accepted into the study, and making a good-faith effort to participate in a study, participants qualified to receive an honorarium, even if they are unable to participate (for example, their car getting a flat tire on the way to the study, or opting to leave for any reason during the study).

The optimal time during the usability testing process to provide an honorarium can vary from study to study. At the discretion of the study designers, participants sometimes receive their honoraria upon arrival for a study, while other study planners provide it at the end of individual study sessions. What's important to know is that giving participants their honorarium at the completion of their session is a convention, not a quid-pro-quo. Honoraria are intended to be a "thank you for your help" incentive, not a tool for coercing performance. In keeping with this philosophy, the amount of honoraria a study provides to individual participants is meant to be "appropriate" but not so high as to be coercive, *e.g.*, "$100 for an hour of participation would be nice" is a reasonable reaction, but "$10,000 for one hour! That would change my life!" might indicate financial coercion and would very likely be inappropriate.

Finally, the consent form also provides contact information for the usability study's leader in case a participant has questions or concerns before, during, or after the session. At the bottom of the form there is typically a signature line where participants may indicate their consent for participating in the study, and it is common practice to provide participants with a copy of the form that they may keep. Consent forms are typically provided as part of the participation welcome process when participants initially arrive for their study session or may be provided ahead of time to give participants more time to review the form and consider their participation in the study.

Drafting a Usability Test Moderator's Guide

With participant recruitment underway (or at least in the planning stages), the next step is typically to define a usability test moderator's guide. This document will outline the processes and procedures associated with individual usability test sessions—what will happen, which questions will be asked, what data will be collected, and how it will later be analyzed and compressed into study findings.

While conducting an individual usability test session, the session moderator follows this pre-defined script to guide participants through a series of tasks related to the product. As participants attempt a given task, the moderator observes and records their interaction successes and notes any challenges that they encounter. Between each task the moderator often interviews participants about their experiences with the task and collects data through a variety of metrics.

A common practice while participants are engaged with tasks is to employ a "think-aloud protocol" where participants voice their goals and impressions as they interact with the product, helping the moderator and any observers to more easily understand the participant's expectations and reactions to what they are encountering. At the completion of the test series, the moderator will examine the data collected, identify key research findings, and present them to the project team.

Drafting an effective moderator's guide involves identifying and understanding which aspects of a product you want feedback on and crafting reasonable scenarios for participants to use to encounter them. For example, a typical research goal for a website usability test series might be to: "Observe study participants as they use the website to complete tasks pertinent to their typical workflow."

Specific observational goals might include:

- What are users' first impressions of the website's initial screens?
- Are users able to identify the purpose and feature offerings of the website?
- Does the website project a cognitive model that supports that of the participants?
- How do participants respond to the website's information architecture, nomenclature, content language, visual design, and overall user experience?
- How well does the website support ease of use?
- Do the participants respond to the website positively, negatively, or neutrally? To what degree?
- Are participants able to complete key tasks in an efficient and satisfying manner?
- What are the website's greatest strengths? Weaknesses?
- Does the website content entice participants to take action?
- What data privacy and security concerns, if any, does the website engender?
- What accessibility concerns, if any, do the websites engender? Is text readable and are text sizes adjustable? Do the products support use by assistive technologies?
- Having defined observational goals in this example, the next step is to craft specific tasks that provide opportunities for addressing the defined goals. Typically,

this results in a series of tasks presented in an unbiased manner that invite participants to examine the product, in this case a website, while a moderator observes and collects data (often through note taking, and via audio/video capture).

A typical task for an e-commerce website, for example, might be "Your friend Katherine has a birthday coming up. Using this website, identify a potential gift for her." In a clinical setting, a web-application task might be "Enter the patient data provided on this paper into the relevant patient record."

Tasks might be presented to participants in writing, read aloud, or presented by other means. As participants attempt the tasks they might be asked to "think aloud" by voicing their impressions and experiences ("I'm looking for something that says 'patient record' but I'm not seeing it.. . it should be here at the top.. . oh, there it is, near the bottom. That's not helpful…").

Once a participant has completed a task, given up on it, or timed out (the moderator feels sufficient time has passed to count as a task failure), the session moderator will typically ask some quantitative and qualitative questions. A common one is: "On a scale of 1 (easy) to 10 (hard) how easy or difficult was it for you to complete this task? Tell me why you gave the task the rating you did…" In this manner, collecting quantitative data (the rating) and qualitative data (the narrative) becomes relatively straightforward.

Once the tasks portion of the participant experience is completed, it's common to ask a few summary questions, typically a rating for the website as a whole, a brief discussion of what is top of mind for the participant that worked well, and what could be improved. Once the session is complete, moderators will thank the participant, provide them their honoraria (if it hasn't been provided already), and escort them from the testing area. Their participation in the study is complete.

Once all the study sessions have been completed, data analysis and the identification of key study findings begin. For a modest usability study, findings may take from a few days to a week or more to draft and put in a format suitable for presenting to those sponsoring the study.

The findings data define a practical, tangible baseline from which to validate the success of current efforts, and to benchmark for evaluation against future development efforts. If designed and executed well, usability tests have ancillary benefits for multidisciplinary client teams—bringing them together. If those sponsoring the study can agree that the study goals are fair, the recruitment process was focused and unbiased, the study tasks were reasonable, and the moderation was not leading, then accepting unpopular findings ("your product has serious interaction challenges") becomes easier.

A usability test series can serve as a unifying element to ease political, technical, and internal confusions that can hamper development efforts, especially when such efforts may impact virtually every organizational unit of a product team's makeup. If the process was fair, then the findings are unassailable, and there's work to be done to make improvements as a shared responsibility.

Why Do Usability Testing?

The systematic process of preparing for and executing a usability test series, whether it's a quick-hit test where you entice some people in a coffee shop to try out your prototype while you observe, or a full-blown test series conducted to support the design of a mission-critical application where lives are on the line (an ICU monitoring interface, an infusion pump settings screen, or an emergency alert broadcast system interface, for example), the process of preparing for, executing, and analyzing the data from usability tests has far-reaching benefits.

To prepare well, teams must focus on and clearly identify their goals, their audiences, and how best to fairly evaluate their product design efforts. They must think, in microcosm, about all aspects of their product design rationales, what each individual or team involved in the process values, and ultimately what the end-users require in order to have successful user experiences.

Identification and direct observation of target audiences typically provides not only straightforward benefit ("we used some jargon where we shouldn't have") but also ancillary benefits that would otherwise be difficult or impossible to uncover ("we thought we had designed it well, but it turns out users value different information presented in ways we hadn't predicted. We need to rethink key screens."). And all of this can happen in general from a few days to about a month's worth of activity time on the calendar.

But again, in a book about the current and future states of consumer health informatics, why are we spending so much ink on usability testing? The simple answer is that it is a highly accessible technique and its use is a bellwether for determining how human-centered a product/service design process you encounter is. Furthermore, even though its typical use parameters have been well defined, usability testing is a highly flexible, multidisciplinary, cross-channel technique that fits any number of product and service-design and development scenarios.

As an example, take the emergence of Augmented Reality (AR) and Virtual Reality (VR) interfaces. In the near future as AR and VR technologies proliferate, what might we do with the ability to simulate environments in increasingly realistic detail and how might we field-test those environments with users? How might we use VR to simulate patient experiences for the purposes of improving them? How might an auto-mechanic in training utilize an AR interface to aim a mobile phone at a car engine and have the engine's parts identified on the phone interface? What implications might that ability have for an automotive training curriculum? For similar capabilities in a medical setting where a surgeon can see vital information presented as a series of AR pop-ups while she works?

As our provision of public health and direct care interventions becomes more synergized across systems, institutional boundaries, and care models, usability testing helps us predict and ground the future by understanding the unbiased needs of those who populate it.

The byword for our time is "ecosystem." While ensuring the usability of individual products is always important, having an unbiased view of the ecosystems associated with products, services, and their use is increasingly vital. It's relatively

old hat to know all there is to know about a particular disease or condition, but what do we know about persons who have more than one disease or condition? How will we learn more about how systems can be improved for efficiency, efficacy, accessibility, and satisfaction?

"Big data" solutions are beginning to find practical footings to conduct en masse analysis of human data, but it remains a human responsibility to see between the numbers and to ensure that as it becomes the present the future is inclusive, reality-based, and human-centric. New capabilities, new directives, and new tools invite innovation and as a foundation, usability testing offers a tremendous amount of merit for helping us keep the "human" in human-centered design.

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Chapter 7
Designing for Inclusion: Ensuring Accessibility for People with Disabilities

Madeleine A. Rothberg

Introduction

When we discuss human-centered design, we can approach it as designing for the most common cases or designing for the most extreme cases. In this chapter, we invite you to consider the benefits to your design from designing for users at the edges—users with disabilities. Users with disabilities present use cases that often mimic the needs of non-disabled users in disabling situations. For example, good color contrast for text is critical to people with some kinds of visual impairments, but every time someone uses a cell phone in bright sunlight they realize how important good contrast is. When you are watching a movie in a noisy place, or in a quiet place where you can't turn on the audio, suddenly captions become as useful to you as they are to a person who is deaf. We call this the curb-cut effect because the need for wheelchair users to be able to travel on and off of sidewalks led to the creation of curb cuts—which turned out to be useful for people pushing delivery carts or strollers, too. The entire industry of roll-aboard suitcases exploded once curb cuts became common.

Health IT can particularly benefit from the input of people with disabilities because in some cases the disability involved leads to frequent interactions with the health care system. In focus groups with participants with a range of disabilities, researchers found that these users had specific needs for improved health IT and had novel suggestions for future features (Karavite, Goldberg, Rothberg, Freed, & Frontino, 2014a). In follow-up research to test the accessibility of a prototype based on these user requirements, some participants remarked that they would use these same features to manage the health of family members who did not have a disability (Karavite, Goldberg, Rothberg, Freed, & Frontino, 2014b).

M. A. Rothberg (✉)
The Carl and Ruth Shapiro Family National Center for Accessible Media at WGBH Educational Foundation, Boston, MA, USA
e-mail: madeleine_rothberg@wbgh.org

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There are specific guidelines developers of technology and other communications products must follow to ensure that they create accessible results. This chapter provides an introduction to those requirements. As you read, remember that every aspect of accessible design can be a curb cut to new and unintended benefits. Include users with disabilities in your usability testing, using the tips in this chapter, both to ensure that your products are accessible and to benefit from the design improvements that are possible when you include the edge cases in your design process.

Introduction to Assistive Technology

People with disabilities span a wide range of disability types with different needs. Understanding the kinds of assistive technology hardware and software (AT) will give you a sense of how people with disabilities use computers and the ways that software and web design can aim for broad accessibility. AT by itself does not guarantee accessibility; accessible design enables AT to offer an accessible experience to users with disabilities.

Screen readers are used by people who are blind to get information from the screen and control the interface. Text retrieved from the UI can be read aloud by text-to-speech software (TTS) or sent to a braille display.

Braille display devices display text as braille characters, using small pins that move up and down to make the braille cells. They also offer control keys for entering text as braille and for navigating the UI.

Screen magnifiers make text and graphics much larger for people with low vision and provide additional mouse control commands to help manage the interface.

Ebook reading tools provide an accessible reading experience by magnifying text, reading it aloud, or translating it to braille.

Alternative input mechanisms mimic the control provided by a mouse or a keyboard to allow users to control the computer with eye gaze, a single switch, a sip-and-puff controller, or many other hardware adaptations. The tool may include a software interface, for example, scanning software that moves through options on the screen to allow a single-switch user to choose one.

Read aloud tools are often used by people with reading disabilities such as dyslexia. The tool can read aloud large passages of text, with a colored highlight on the current line if needed. These tools do not generally include the complex control features needed by screen reader users.

System tools often play the role of AT; built-in features for enlarging documents, using software from the keyboard, changing font colors and background colors for better contrast, and even spell check and simple read aloud capabilities are part of modern operating systems and software tools.

Demographics and Projected Numbers

In the USA, as of 2010, there were more than 56 million people with disabilities of all kinds (Brault, 2012). This represents almost 19% of the population. However, older people are three times more likely to have a disability than younger people, so the aging trends in the population suggest that the number of people with disabilities will increase substantially in the coming years (Field & Jette, 2007). Not all people with disabilities have difficulty using technology or need AT, of course. But many do, and creating accessible technology can contribute to independence and reduce the extent to which physical changes, due to aging or other causes, result in an inability to function.

Universal Design

Universal design, originally envisioned for the built environment, is a term first used by Ron Mace, an architect and a wheelchair user. He imagined "a commonsense approach to making everything we design and produce usable by everyone to the greatest extent possible" (Institute for Human Centered Design, 2008a). The principles of universal design can be applied generally to technology design as well, with the need for equitable use, flexibility, intuitive use, perceptible information, tolerance for error, and low physical effort (Institute for Human Centered Design, 2008b) all finding appropriate expression in software design.

Universal design for software must ensure that user interfaces can be perceived in multiple ways and controlled with multiple inputs. Access through ATs as well as ease of use without ATs is critical. The industry-leading guidelines, the Web Content Accessibility Guidelines 2.0 (WCAG), offer a framework for accessible software and websites through a series of checkpoints organized around four principles of digital accessibility (W3C, 2018a). Content must be:

- Perceivable,
- Operable,
- Understandable, and
- Robust.

Rather than design for one specific AT or one specific disability, universal design emphases maximizing inclusion by creating flexible, multimodal content that can adapt to a wide range of user needs.

Usability Problems and Accessibility Problems Combine to Create Road Blocks

General usability is the bedrock of accessible design. A well-designed, user friendly UI has the information structure that an accessible site needs. What remains is to ensure that the structure is communicated programmatically, through appropriate code, rather than just through visual design. As an example, most websites have a set of internal text heading styles. If those styles are coded visually, with font sizes and colors, but without HTML's heading markup, users who are blind won't be able to quickly skim the page structure. Add heading markup with consistent, appropriately nested headings, and the same page can be explored quickly and easily with screen reader commands that move from heading to heading.

For a person using AT the process of navigating a web page is generally less efficient and more error prone than the same process for a user without a disability. Navigating by keyboard through a large number of links is slower than using a mouse to go directly to your target. Using a screen reader or screen magnifier is a bit like looking at an interface through a straw: only one area at a time is in focus. A screen reader is an inherently serial way to read. When the screen is full of unstructured text, the screen reader reads from top to bottom, left to right, without the kinds of visual cues that sighted users use to decipher the structure of a Web page.

If a UI is poorly designed, inconsistent, and difficult to use for general audiences, the additional impact of AT use will make it even more difficult for a user with a disability. It takes longer to explore and find useful information, it is harder to fill out forms if they are poorly labeled, and it is more difficult to recover from an error when the context is not clear. For this reason, creating good structure and a predictable layout, offering semantic markup for forms, and ensuring errors can be easily reversed is crucial to making your technology accessible.

Accessibility on the Web, for Mobile, and in Real-Time Events

Legal Framework

Legal accessibility requirements vary in different contexts, though the basic steps needed to achieve accessibility do not. The US federal government is required to ensure the accessibility of all electronic and information technology it develops, procures, maintains, or uses under Section 508 of the Rehabilitation Act of 1973, as amended in 1998 (Section 508.gov, n.d.). Federally funded schools and universities are required to provide accessible educational experiences under Section 504 of the Rehabilitation Act (U.S. Department of Education, 2015).

The Americans with Disabilities Act (ADA) provides requirements for a range of institutions (ADA.gov, n.d.).

Title I prohibits discrimination against people with disabilities in employment. This means that software necessary for a person to do their job must be accessible to them, or a reasonable accommodation must be made.

Title II covers state and local governments and requires their programs, services, and activities to be accessible to all.

Title III prohibits discrimination in places of public accommodation, defined as businesses that are open to the public and fall into one of twelve categories listed in the law; doctor's offices are included.

Case law has not yet definitively settled whether the internet is a place of public accommodation. Regulations that were at one time expected from the US Department of Justice to clarify the application of the ADA to the internet and mobile technologies have not been released. However, the "ADA is a broad civil rights statute mandating full participation of disabled people in all aspects of society" (Feingold, 2017) and avoiding responsibility for accessibility by waiting for further regulations is not a forward-thinking approach.

For health IT specifically, requirements in the Affordable Care Act's Meaningful Use rules incorporate Web Content Accessibility Guidelines (WCAG) 2.0A requirements for consumer-facing systems for viewing, downloading, and transmitting personal health data (Centers for Medicare and Medicaid Services, 2016).

For international contexts, different frameworks apply. Both Australia (Disability Discrimination Act, 1992) and the United Kingdom (Equality Act, 2010) have civil rights laws in place for which the details of enforcement are determined in court; precedent thus far shows that having made a good faith effort at accessibility by following well-known international guidelines such as WCAG 2.0 is the best defense.[1] The European Union (2014) has established Mandate 376, which requires member states to have accessible public procurement of information and communications technologies.

Canadian law includes the Access for Ontarians with Disabilities Act which lays out a phased increase in accessibility requirements over time (Ontario, Canada, 2005). The Accessibility for Manitobans Act (AMA) has become law and specific standards for Information and Communications are in development (Manitoba, Canada, 2013). At the time of this writing, the Canadian federal government has introduced legislation which would take this model to the federal level (Bill C-81, 2018).

[1] See "What standard is required?" on the page "Disabled access to websites under UK law" (2011). Retrieved from: https://www.out-law.com/page-330.

Basic Rules for Digital Accessibility

Making digital materials accessible, in many cases, doesn't cost extra when included in the initial planning and development process. Many aspects of web accessibility result from following programming practices that make the structure of information evident both visually and in the code. There are some accessibility features that require a bit of extra work, but those often have side benefits for the site and its users, such as the captions described above. Retrofitting—the process of repairing a website or product that was not made accessible when it was first built—will of course add to development costs because it adds an additional step to the process. Include accessibility in your plans from the start by following these basic principles. Consult the resources listed throughout the chapter for more details.

Keyboard Navigation

An accessible website must be able to be used entirely from the keyboard. Some users find a computer mouse difficult to use because of problems with fine motor control, while others have difficulty seeing the screen. As mentioned earlier, some kinds of assistive technology mimic the keyboard to provide input controls for users with physical disabilities. (Other AT mimics a mouse, so ensure that everything in your site can be used from the mouse alone, too, other than text input. This is generally the way designers assume a site will be used so it may not require any changes in design.)

Keyboard access is easy to test yourself—just try to use a website without touching the mouse or trackpad. Use the tab key to move around and watch for visual clues that tell you what item has focus. Try to fill out a form using the tab, enter, and space bar keys to navigate and make selections.

The most common problems for keyboard navigation are:

- *Turning off the visible focus*: Web browsers each have their own default focus style, either a thin dotted line or a blue outline. Designers who don't like that appearance often suppress the visible focus. This makes it impossible for keyboard users to know where they are on the site.
- *Focus is visible but hard to see*: The default focus appearance is sometimes hard to see around certain elements. For example, the thin dotted line in some browsers blends into dark backgrounds, while the blue outline can merge with images and blue icons. Because the designer cannot control which browser is used, in most cases, and the different browsers have such different defaults, it is hard to ensure the focus is always clearly visible.
- *Elements not in the keyboard tab order*: If some UI elements are not in the keyboard order, keyboard users will never be able to activate them.

To ensure keyboard accessibility, include all active elements in the tab order, and design a custom focus appearance with CSS that matches your design scheme and provides good color contrast.

Structure and Skippability

Information design for the web is often focused on the visual appearance of the site, but accessibility requires making the structure fully evident in the site's code. These features will help.

Headings: Use sensible and consistent nested heading levels to show the structure of each page. Use heading level 1 for the page title, heading level 2 for major page sections, and so on.

Regions: Convey the layout of the page with landmarks and regions, indicating the navigation area, the main content, and sidebars.

Skip links: Once every part of your page is reachable by keyboard, it can take a long time to move past all the top navigation to get to the main content of a page. Offer a skip link as the first page element to help users go immediately to the information they came for.

Colors and Fonts

Ensure your text is easy to read.

Test for color contrast: A number of free tools can tell you if your color combinations meet contrast requirements.

Use relative font sizes: While most browsers can enlarge all kinds of fonts for users who need to, in some cases absolute fonts will not enlarge properly.

Don't use color alone: If color is the only change to an element that has focus (from the keyboard or a mouse hover) or the only way to distinguish between two types of information on your page (such as body text versus link text), add another visual indicator (a shape, underline, or outline) to ensure that the change or difference is easy to perceive.

Forms

Ensure users can fill out forms by following basic rules.

Label and group form controls: Use standard HTML controls for default accessibility features and add explicit label/input matching.

Test that you can use the form from the keyboard: Try out your forms, including select lists and radio buttons.

Present error messages accessibly: Use semantic structures so that screen reader users are aware of error messages or field-specific instructions.

Multimedia

Closed captioning for broadcast television has been widely available for many years (WGBH, n.d.). Tools and techniques for making multimedia accessible emerged as video on the web became more common. Basic video accessibility requires three things.

Captions are a synchronized visual and/or text alternative for both speech and non-speech audio information needed to understand the media content (WCAG, 2008a).

Audio description is narration added to the soundtrack to describe important visual details that cannot be understood from the main soundtrack alone (WCAG, 2008b).

Accessible controls are needed to ensure that keyboard and AT users can operate the video player.

Interactive multimedia, such as simulations and games, can require more customized accessibility. Authors need to provide access to all controls, but also to plan an efficient and effective way to communicate the status of dynamic elements in real time. This is an area of active research. Some interactive experiences can be made accessible relatively easily, while more complex or highly visual interactions may be difficult to adapt. Guidelines for game accessibility (Game Accessibility Guidelines.com, n.d.; Able Gamers Foundation, n.d.) and interactive accessibility (Benetech, 2017a) are available online.

Order of Content Within Messages

When you have a long or complex set of information to give, think about the order of the content within the message. Start with the newest or most important information, or with a brief overview. Users who are browsing with a screen reader will hear that first and can decide whether to listen to the entire message or move on to the next part of the interface.

How is Mobile Different?

Your site should be tested for mobile as well as desktop accessibility. Most techniques are the same and the industry trend toward responsive sites rather than separate mobile code makes it easier to deliver an accessible site to users on all sizes of device. Differences in screen size and touch UI create some additional areas to pay attention to for accessibility, which are described in the W3C's Mobile Accessibility guidelines (2015).

Built-in Accessibility

Some applications offer accessibility features as part of the content such as widgets for changing text size or reading text aloud. Generally, if you are building mainstream content, you will get the best usability if you follow accessibility guidelines and use accessibility APIs native to the platform for which you are developing. This will allow AT users to continue using their tools as they have them configured rather than needing to learn a new set of commands specific to your application. An exception may be necessary for interactive resources such as simulations or games, as discussed above.

Basic Rules for Non-Digital Accessibility

Non-digital resources and interactions must be accessible, too, of course. The techniques will be different, but the goal of ensuring everyone has access to information and the ability to benefit from and contribute to events is the same. Information on including people with disabilities in user testing, specifically, appears later in this chapter.

Documents

Printed documents should be clear and readable. Specific guidelines for standard-sized print and large-print documents are available from a number of good sources, including the American Printing House for the Blind (n.d.) and the Canadian National Institute for the Blind (2006).

And for those who cannot read print at any size, an accessible alternative might be an online version (built accessibly, of course). Some users will also want hard-copy braille, but keep in mind that not all blind people are braille readers. In some situations, an audio file recorded by someone who understands the material is a good alternative.

Events

Plan an accessible event by ensuring access to the physical space, clear communication in both directions, and timely access to handouts. Use a comprehensive checklist such as the Check List for Planning Accessible Events from Cornell University Student Disability Services (2013) or the Guide for Hosting Accessible and Inclusive Events from York University (2013).

Use Cases

Emergency Alerting

Ensuring that all members of the public are safe in an emergency is a high priority (FEMA.gov, 2017). Alerts can be made accessible using all the techniques described for web accessibility: captions must be displayed with audio alerts and audio alternatives must be available for visually broadcast messages. Sending messages directly to users' personal devices has become the preferred approach as smartphone usage reaches near ubiquity. Users are assumed to have any assistive technology they need already installed on their own device. As long as the emergency alert message is sent in accessible text or a multimodal format that meets a range of sensory needs, it is likely to be received (National Center for Accessible Media, 2009).

Accessibility of emergency messages is a clear example where ensuring you meet the needs of travelers with disabilities will improve everyone's experience. Having multiple methods of receiving alerts provides flexibility for people who didn't quite catch the audio, people who read faster than they listen, people who are staring at their cell phone and won't see a visual sign, and so on.

Public Health Advisories

When designing a public health outreach campaign, such as a vaccination campaign or food safety alert, consider a wide range of accessibility needs. Ensure your message goes out in a variety of media, such as radio, print, and online.

Print and online materials should follow design guidelines for visual clarity and contrast, as well as using clear language to be understood by as many consumers as possible. Videos should be captioned and should offer audio description if there are key visual elements that aren't communicated in the soundtrack. Designing the script for the video to include all relevant information will remove the need for audio description. Usability and accessibility go hand in hand to reach the largest audience, including people with disabilities.

References to Standards and Further Reading

The following resources will provide more detail than can be included here:

The World Wide Web Consortium's (WC3) Web Access Initiative, especially Getting Started with Web Accessibility (2018b);
Mobile Accessibility: How WCAG 2.0 and Other W3C/WAI Guidelines Apply to Mobile (WC3, 2015);
Accessible Digital Media Guidelines (National Center for Accessible Media, 2009); and
Image Description Guidelines (Benetech, 2017b)

Accessibility for Health IT

Health IT features complex information tasks. Users may be receiving critical information, making high-impact decisions, and managing concerns about privacy. Users with disabilities are no different. Their goals (Karavite et al., 2014a) for using health information systems are fairly similar to the goals of the general public (Lake Research Partners, 2010). In their study entitled "Consumers and Health Information Technology: A National Survey," Lake Research Partners found that adults with chronic conditions were more likely to benefit from having access to a health information portal. Since many (though not all) people with disabilities have chronic conditions, it makes sense that users with disabilities included in the study Accessible Designs for Personal Health Records showed strong interest in the features a personal health records system can offer (Karavite et al., 2014a).

People with Disabilities Can Be High-Use Consumers

Some people with disabilities have complex health conditions, manage medical equipment and supplies, and must coordinate their care with a number of caregivers and medical staff. These needs make them well-suited to inspire highly useful HIT.

Some people with disabilities have no unusual health concerns, of course. This includes many people with visual impairments or those who are deaf or hard of hearing, who require attention to accessibility in IT but are not necessarily large volume consumers of health services.

The use cases suggested by participants in the Accessible Designs for PHRs study (Karavite et al., 2014a) range from features that are common now, such as appointment scheduling and prescription renewal, to unmet needs such as:

- Scheduling multiple appointments at coordinated times to reduce transportation hassles for those using paratransit
- Communicating information needed to ensure a successful visit, such as the need for interpreters or special equipment required for transferring a patient to an examination table
- Insurance supports, such as information about costs and coverage, and tools to manage referrals and appeals
- Tools for tracking acquisition, maintenance, and use of medical equipment including wheelchairs
- Educational materials specific to the patient's needs
- Care plan tools that allow users to add instructional videos and share the care plan with home health aides and other caregivers.

While some of these features are more disability specific, many will be useful to a wide range of users. Many users have insurance concerns, would like customized health education material, or sometimes need to coordinate multiple appointments.

In fact, one participant in the user testing, who herself had a physical disability, commented that she'd like a system with these features for managing her aging mother's health care.

In the accessibility field, we sometimes call people without disabilities "temporarily able-bodied" to remind ourselves that those who do not have a disability today will most likely acquire one as they age; here we have an additional reminder of the general need for accessibility-related features, because many people care for aging parents.

Use Cases

Accessible Health Education Materials

Accessible design for health education is critical to ensuring that every patient has the information they need to manage their medical condition. Offer flexible materials that adapt to user's needs, including multiple languages and video, text, and still images when possible. In a prototype designed to assess consumer preferences for accessible health IT (Karavite, Goldberg, Rothberg, Freed, & Frontino, 2014c), providing a range of materials with clearly labeled links allowed consumers to find the most helpful educational resources for them. Following all the basic web accessibility guidelines ensured the page was as accessible as possible for participants with visual and physical disabilities (Fig. 7.1).

One concern that emerged from user testing was the need for health education materials in American Sign Language (ASL). Deaf participants felt that ASL was a crucial piece for critical communication; after clinician review to ensure the materials were high quality, an ASL video was added to the prototype and satisfaction for deaf participants improved.

Online educational systems can support multiple libraries of materials on the same topic. This approach can meet the need for multi-lingual support, including sign language. Adding a library of resources aimed at young patients and one for patients with cognitive impairments would further enhance accessibility. As much as possible, each resource should have basic accessibility features including captions for videos and accessible markup for web pages, but the power of a network of resources can overcome some accessibility flaws when consumers can choose the resource that meets their needs.

Care Plan

Patients with physical disabilities often rely on a care plan which lays out the assistance they need with activities of daily living. These plans can be quite complex and can include the use of medical hardware. Patients often need to train new care

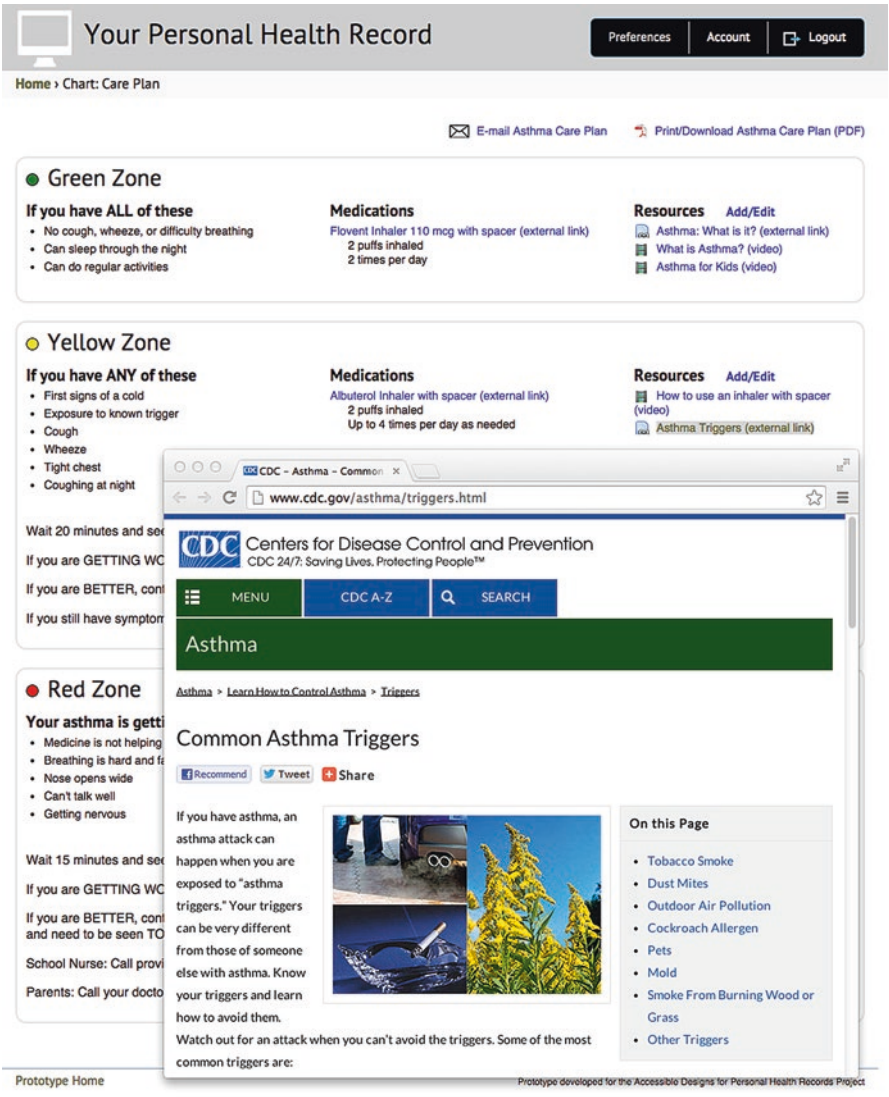

Fig. 7.1 Prototype personal health record (PHR). Source: Karavite et al. (2014c)

assistants or family members to assist them. This can be made easier with a flexible digital care plan. A prototype of such a system (Karavite et al., 2014c) shows features that consumers value: clearly laid out information, easy editing features, and the ability to add new videos to document how this patient uses their equipment, to show to future caregivers (see Fig. 7.2).

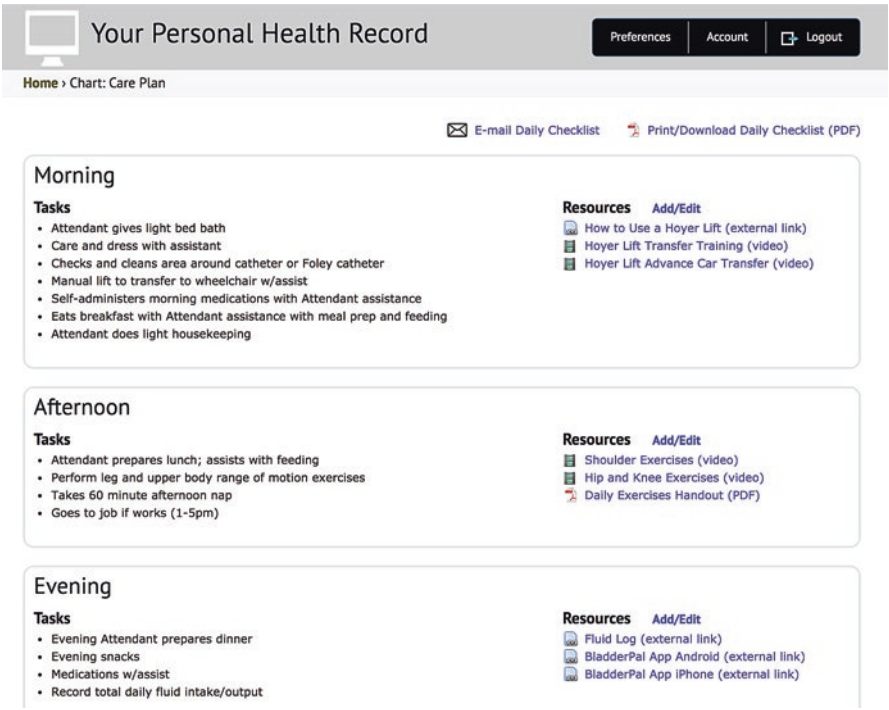

Fig. 7.2 Prototype showing clear layout and editing features. Source: Karavite et al. (2014c)

Equipment List

Another feature of this prototype (Karavite et al., 2014c) with impact for users with a range of disabilities and other health care needs is the equipment list. It allows users with medical hardware to track information about each piece of hardware, including warranty and repair information, insurance tracking, operations manuals, and more (see Figs. 7.3 and 7.4).

Consumers noted that this format could also be used to manage medical supplies by tracking amounts ordered, order dates, and purchase prices to assist in re-ordering supplies regularly. Participants saw clear value in a system designed to track medical information securely, accessibly, and under their own control.

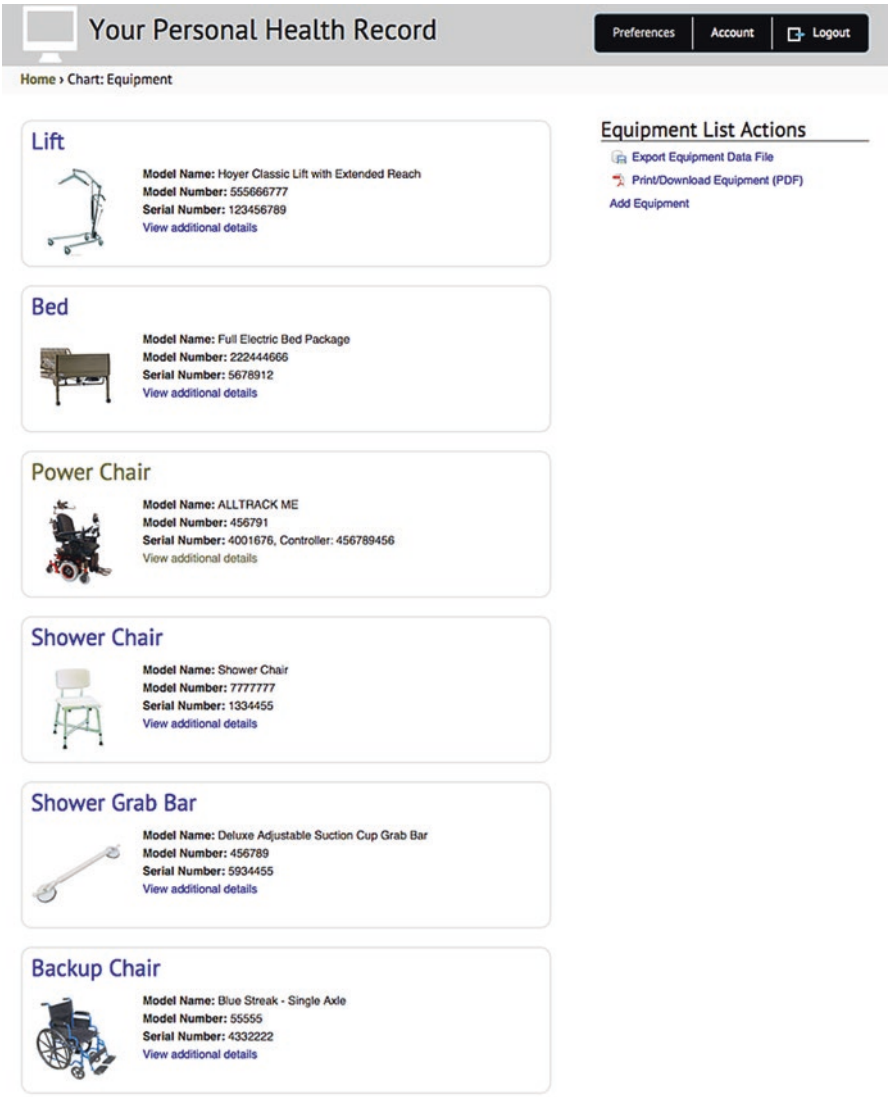

Fig. 7.3 Prototype equipment list. Source: Karavite et al. (2014c).

Including People with Disabilities in Interface Design

Accessibility vs. Usability

The design process aims at providing usable products and services. Usability is not separate from accessibility, but instead is intertwined with it. If a website meets all the technical requirements for accessibility but is difficult to use, it will fail users

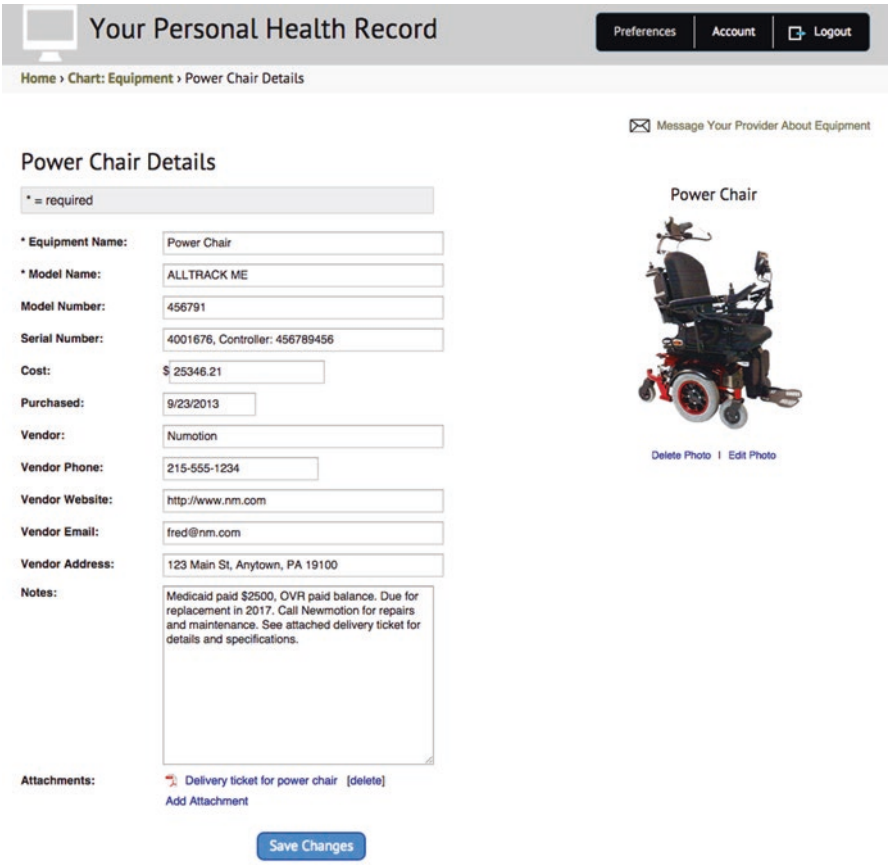

Fig. 7.4 Prototype equipment Details. Source: Karavite et al. (2014c)

just as much as if it was inaccessible. For this reason, including people with disabilities in user testing is critical to the true accessibility of your design. And the focus on simplicity and clarity that some users with disabilities need will make your design better for all users.

Personas

When your design process includes personas, journey maps, and similar techniques for understanding users, include personas of people with disabilities. Starting with existing personas, and with a bit of additional research about your own users, can make the accessibility requirements more evident and help the entire team take ownership of the need to follow accessibility guidelines. A set of personas

describing a range of abilities is included in the book A Web for Everyone, by Sarah Horton and Whitney Quesenbery, and the personas are available online (Quesenbery, 2014).

User Testing with People with Disabilities

If your user testing does not include people with disabilities, you will most likely miss important accessibility problems, even if you have followed accessibility guidelines and used expert review during the development process. This is for the same reason that you do user testing with any audience: diverse users will use your product in diverse ways and uncover problems you didn't see during development.

Including people with disabilities in user testing will require attention to some areas you may not have considered in the past. With good will, politeness, and some preparation you can successfully integrate users with disabilities into your testing cycle.

Prepare: Consult experts and consumer groups, do some background reading, and don't be afraid to ask plenty of questions. It is better to ask someone what accommodations they need than to assume and miss something important. Have study documents such as consent forms available in a variety of formats, and be ready to read them aloud if that is the best accommodation. Allocate extra time for this and other changes to your usual methods. Compensate for transportation issues participants may have.

Recruiting: Advocacy and consumer groups, universities and other schools, and well-connected members of the community are all good contacts for recruiting people with disabilities. Many groups are "low incidence" which means they are not a huge part of the general public, so your recruiting strategies will need to be targeted.

Accessible space: See the resources listed under events, above, for information about ensuring the space you use for user testing is accessible. If your usual testing space isn't accessible, you may need to find another location for some test groups. Participants who have trouble with transportation will appreciate you coming to a place they already visit or can get to easily, so you may want to do that even if your space is technically accessible.

In the moment: Be patient and follow the cues of your participants. Expect guide dogs and care attendants, depending on the disabilities included in your study. Be flexible if your usual moderating techniques don't work. Offer breaks and snacks as needed.

Interviewing tips: If you are used to moderating focus groups using eye contact, you will need more verbal techniques when working with participants who are blind. If you like to use small toys for ice breaker activities, those may not work for some participants with physical disabilities. In general, be flexible. You may find you need to improvise on the spot to devise alternative versions of practices you weren't previously aware you were using.

Conclusion

Health IT practitioners strive to build an ecosystem of technologies that support health practitioners, patients, and caregivers to reach the best health outcomes possible. This cannot be achieved if people with disabilities in all of those categories cannot use the technology provided. Ensuring accessible, usable design must be a goal of every development process. By following principles of accessibility and usability, testing rigorously, and including participants with disabilities in user testing, the field will move forward toward greater inclusion. And with that will come the benefits to all users of more adaptable, usable, and feature-rich systems.

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Chapter 8
Understanding the Human-Centered Design Process

Christopher Hass

Get Me a Usability!

My office phone rings and it's a product manager calling from a *Fortune 100* company you've likely heard about. After some initial pleasantries, he informs me that someone on one of his teams has suggested that before their next product launches to the public, they should "get a usability." He adds: "I hear you guys are good with that. Can you get me a usability before this product launches in two weeks?" As a seasoned consultant, I know that the answer to this question, no matter how ridiculous it seems, is "yes." With humorous visions of pulling a giant box of "usability" off a nearby shelf to sprinkle on his company's product, I get some additional details: what is the product? Who is the target audience? What is the product meant to accomplish?

After nearly 20 years of fielding these calls, I'm rarely surprised by how clients find their way to me, and despite the relatively ham-fisted request described above, I'm very glad to be able to help. What this well-intentioned product manager is telling me is that someone in his company, perhaps he himself, has some reservations about the usability of the product that's about to go live. And that is a valuable concern to voice at any point in the product development cycle.

Human-centered design activities, often referred to as "usability" techniques, are maximally helpful if begun early in the product development cycle. But like any good physician with an ailing patient, I'm always glad they've found me. Not me specifically, even, but the human-centered design process. Thanks to generations of human-centered design practitioners and educators, and the tireless work of "usability" related professional organizations, like the User Experience Professionals' Association (UXPA, http://www.uxpa.org) and the Association for Computing Machinery's Special Interest Group for Computer-Human Interaction (ACM

C. Hass (✉)
Boston, MA, USA
e-mail: chris@createwww.com

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SIGCHI, http://sigchi.org), and many others, these calls are nominally rarer. As the virtues, benefits, and return on investment of human-centered design activities have become more widely adopted by companies, organizations, and government agencies, my clients are generally better informed about my work as a user experience (UX) practitioner than they used to be. For every one of my "get me a usability" calls, there are a dozen or more groups reaching out earlier in the design and development cycle. This is an improvement, but still the ubiquitous "can you give me a usability?" questions abound.

For a last-minute client I do what I can, providing an expert review (giving a quick but thorough review of their product based on my professional experience and making "quick hit, high impact" recommendations) or a fast usability test with members of their target audiences (having target audiences individually use the product to perform key tasks, observing their successes and difficulties, and talking with them about what would improve their experience).

For other clients with more time, there is an opportunity to provide more systemic human-centered design benefit. Squinting my eyes across all the various human-centered design techniques available, it may be helpful to provide an overview of what a "typical" product design process is like. Whether you're designing a website, mobile application, human service, or physical product, and while all projects are different, on balance, the phases described below may be generalized across industries for our purposes here.

What specifically happens to ensure that a product is maximally usable, efficient, accessible, effective, and satisfying to use? Building on Chap. 5 (Hass & Edmunds, in press), the following are potential activities that can be used to good effect across the phases of product and service design and development. They are mainstays of human-centered design techniques. Not all activities are required for success, and there are many more that could have been included, but what follows outlines a sample discovery and design phase for a hypothetical product or service, for instructional purposes.

As always, your experience will vary and we encourage you to seek out additional information about the breadth and depth of human-centered design techniques and best practices, since new information becomes available online on a regular basis. Key search terms include: human-computer interaction (HCI), human factors (HF), user experience (UX), usability, accessibility, and user-centered design, among others. (For more in-depth information, please refer to Albert & Tullis, 2013; Berger, 2016; Goodman, 2012; Mitchell, 2007; Rubin & Chisnell, 2008; and www.usability.gov.)

Sample Discovery Phase

Imagine that my corporate caller hadn't contacted me 2 weeks before product launch, but instead at the point where the company's leadership first began to envision their product. If instead of "help us before it goes out the door," the request was

"help us envision a usable and effective product from the start." (Full disclosure: I love those calls!) What might I suggest? Given even a little lead time, our collaboration might have begun like this.

Kickoff Meeting

Projects and discovery phases often begin with a kickoff meeting. This serves as a formal project start where all parties present represent the core product team. Kickoffs often include organizational stakeholders, an organizational project lead, a product manager, a project manager, the staff who will be involved on a day-to-day basis, and any specialized technical experts who will be involved in the project. Often, in my case, as part of an interaction design agency, our team includes a user experience director/designer, a user experience researcher, a visual designer, a developer (if the product is digital), and a project manager.

During the kickoff meeting we begin by holding a formal discussion with all parties present to define a project plan outline with rough milestones and dates, outlines of design review cycles, planned activities, and the like. We anticipate that the planned schedule will include focused activities interspersed with appropriate, flexible, pauses for internal and client review cycles.

Specific kickoff meeting goals are often to:

- Define a project timeline and select dates for key project activities.
- Identify key target audiences and their relevant demographics.
- Review programmatic goals and objectives.
- Review product-specific goals and objectives.
- Review the technical goals and objectives for any involved technologies.
- Identify prior research, data, and literature pertinent to the project.

Data and Literature Review

In a data and literature review, the product design team consumes available information a client or product team may have on hand, either from prior activities, in-house or out-of-house knowledge of relevant guidelines and regulations, and other material relevant to the work at hand. Sometimes we conduct reviews of available data analytics and conduct searches for academic and other relevant published papers. Generating or reviewing this information helps unify the team's approach and illuminates key guidelines and considerations at the start of the product design process.

Stakeholder Interviews

It may seem counterintuitive, but organizations that desire to envision, build, and offer a product to their constituents frequently leap quickly from idea to execution often without even rudimentary due diligence to identify whom, specifically, a product is designed for, how it will be used, and most importantly, how it incorporates into or enhances their workflow and well-being. Product design directives can come from multiple quarters within an organization and frequently cross- team boundaries. Ensuring that their vision is collective, clearly articulated, and documented is an important first step to maintaining the institutional focus required to bring a successful product or service to those it is designed to support.

To build that clarity, stakeholder interviews are an effective and essential activity to support human-centered design processes. A typical stakeholder interview is a scheduled discussion between a researcher and leading members of a product or service team to provide programmatic insights from that stakeholder's perspective. Interviews are typically conducted one-on-one to help stakeholders to speak freely, and interview questions typically center around "What is it you hope to accomplish?" "Who are the target audiences for the product/service?" "What will success look like?", and "What challenges do you see for this emerging product/service?"

Conducting stakeholder Interviews early in the design process with internal strategic thought-leaders often enables project teams to identify hidden perspectives and to prioritize business goals directly against end-user information needs (which are themselves, gathered in parallel or shortly after stakeholder interviews). This quick and informative process, often just an hour or so spent interviewing each thought- and program-leader associated with the product, lays the groundwork for project efforts and provides reference documentation that all members of the project team and their leadership can use to ensure that project efforts are achieving stated goals and objectives over time. A typical stakeholder interview series may be 5–10 persons, or more robust, depending on the situation at hand.

Most importantly, stakeholder interviews help to identify key success factors for evaluating the efficacy of the approach itself. We can attenuate the number of interviews up or down as appropriate without difficulty in the case of small, medium, or large efforts. The goal of stakeholder interviews is typically to define and refine the project team or organization's collective understanding of the proposed product's audiences, purpose, current or envisioned successes and challenges, and to identify programmatic design and interaction priorities.

Once these interviews are complete and data from multiple interviews has been aggregated into a single summary report, that report can serve as a reference for all members of the project team to use in their decision making from that point forward. This can help foster an "apolitical" process where all stakeholders can see their views reflected in the collective vision, be assured that their concerns have been noted, their views of success captured, and that they are on the same page as their colleagues, each from their own perspective. (And if they're not, the report provides specific points for discussion and subsequent comparison with the user needs to be collected in the next activity.)

As obvious as it seems, ensuring that stakeholders share a vision, articulate their understanding of prioritized goals and what their product/service should be and do, is an important step. In the case of my last-minute caller asking for a sprinkle of usability before their product goes live, an abbreviated version of this step is appropriate and important.

User-Needs Research

While capturing stakeholder views is undeniably helpful, and can uncover potential differences between programmatic teams, user-needs research is arguably the most helpful activity in an initial discovery phase. User-needs research is a hallmark of human-centered design approaches. The goals of user-needs research at this stage are to—as their name says—foster an unbiased, unflinching understanding of how core constituents, who may (or will) be asked to use the product in the future, are currently going about their relevant business. (Other resources include Code for America, Jan Dittrich's guide to finding user needs on Creative Commons, UX Collective blogs on knowing users' needs, and Coursera courses on usability, information design, and entrepreneurship.)

When choosing an appropriate user-needs research activity, many potential activities are available. We might conduct a benchmark usability test of an existing product, or a product's competitors, to see how it is being used today, and to glean insightful inspiration for envisioning more ideal solutions. Surveys, focus groups, individual interviews, field observations, usability tests, contextual inquiries, co-discovery activities, competitive analyses, and ethnographic research (examining the culture associated with product or service use, not just use itself), among others, are all techniques that may be used to good effect, including those that you might invent.

The goal in selecting an appropriate user-needs research technique is to identify what is reasonably observable, measurable, and otherwise capture-able that will contribute to an understanding of factors relevant to how the product will be used, what challenges it might face, or what opportunities might exist to exceed the efficacy of the solutions currently available. Typically, I select one or more techniques and scale them based upon what can be reasonably accomplished by available personnel, budget, and in the time allotted, in order to gather foundational insights into and observations of user's current information and/or interaction needs balanced against the level of "certainty" or data reliability required.

In other words, I seek to identify the minimum level of intervention appropriate for obtaining actionable insights that will enhance the product and project teams' foundational understanding of what their product will need to accomplish. It helps to foster creativity and innovation, and if business goals and end-user goals are at odds with each other, it will convince project leadership that the discrepancy between business goals and end-user needs is significant enough that they need to rethink and potentially pivot their approach prior to outlays of design and development funds.

User-needs research activities, as one can imagine, involve identifying, recruiting, and engaging end-users (those who are intended to use a product or service) in the research activities. In general, recruitment requires collaborating with a client team to identify core audiences with reasonable specificity, (e.g., "persons with cardiac-related conditions between the ages of 45 and 75" rather than "patients"), drafting a study description, a recruitment screener, and scheduling participants.

A study description, or flier, is a brief description of the study with a call to action for potential study participants. For example, a simple flier might read: "Participate in a Usability Study! We are seeking hospital intake administrators with six-months to two-years' experience to participate in a usability study of administrative software in development. Participation will have a direct impact on a product intended for use by hospital administrators. Participation generally takes between 1 and 2 h and provides an honorarium of $300. If you are interested, please call: [phone number]."

A recruitment screener typically consists of about 10–20 questions that identify potential study participants as appropriate or inappropriate for the study to be conducted. In the USA and abroad there are many legal protections for study participants and guidelines for practitioners to adhere to in order to ensure that their recruiting practices are fair, inclusive, unbiased, and adherent to professional research standards. Once a recruitment screener has been drafted it is submitted for approval, usually by the research team, the client, and in many cases an Internal Review Board (IRB) that may comment on and ultimately approve the screener. (It is worth noting that despite the name "Internal Review Board," sometimes IRBs are external to an organization or research team, acting as consulting experts or corporate partners.)

Recruitment of participants generally takes about 1–2 calendar weeks of outreach by consulting recruitment agencies or research teams to distribute the study flyer (through digital and analog means) and to screen potential participants using the recruitment screener. Recruitment agencies will utilize pre-purchased lists of potential study participants and a battery of outreach techniques to reach target audiences including social media, professional connections, visits to relevant facilities, and cold-calls.

In general, recruitment agencies are paid a pre-determined rate (negotiated up front) for each person scheduled for the study. Recruitment agencies come in all sizes from independent practitioners to large-scale marketing and usability recruiting agencies. In many cases organizations of all sizes will handle participant screening and scheduling, send reminders to participants in the days leading up to the study, and ensure that participants receive any honoraria associated with the study.

Once participants have been recruited and scheduled, typically over the course of a few consecutive days, they will next, if all goes well, participate in the research activity you have planned for them. Participation may mean engaging in a phone interview, a survey, a focus group, a usability test session, or any number of other activities to help you understand their information and interaction needs.

During this phase, researchers gather information relevant to the product/service to be designed by asking questions about current use practices, what tools they use,

how effective those tools are, what common workflows look like, what's working for them and not working for them, and what they might envision as an ideal solution for the future. In this manner, we can generate a post-study summary-findings report for comparison with the stakeholder vision captured during the stakeholder interviews and gather insights to support the design of a better solution.

If both stakeholders and users are aligned, we have gained certainty (that the project team is on the right track) and gained insights into participants' workflows, emotional and professional needs, and what, in general, a successful product or service will need to accomplish to be better than the options currently available.

Heuristic Evaluation/Expert Review

For my corporate caller with so little time left before his product goes live, one effective and often rapid activity is to have a team of consulting experts review it and make recommendations for short- and long-term fixes based on their expertise and guided by established industry best practices and heuristics. Thus, an heuristic evaluation is a process by which one or more experts review an existing product, product design, or service to benchmark it against industry standards from a variety of perspectives. The goals are to identify aspects of the interaction design that are successful and those that could use additional user experience, content strategy, interaction design, visual design, technical design, technical implementation, or user feedback—all in a time-efficient manner.

While it's nearly always more advantageous to involve end-users in research activities, this process can offer an effective alternative to a benchmark usability test (for example) if the evaluation team is knowledgeable and time, budget, or access to users is limited. During an heuristic evaluation, a review team will develop a review guide which identifies the process and scope of the evaluation, whose screens or use-scenarios are to be undertaken by reviewers, a summary description of key audiences that the reviewers are standing in for, and any relevant metrics and heuristics related to interaction design, screen design, ergonomics, and other industry guidelines relevant to the product/service being reviewed.

Once a guide has been developed and approved by the review team and/or its leadership, reviewers typically evaluate the product or service independently, noting from their perspectives key product/design successes and opportunities for enhancement. Common review topics include: nomenclature, navigation, content, visual design, the product's cognitive model, ease of use, performance according to design best practices and industry standards, and overall usability. This may take one or more days depending on the complexity of the review, but once individual reviewers have finished, the team reconvenes to discuss and prioritize the group's collective findings. Generally, they draft a summary-findings report with recommendations and present it for discussion to the client team.

All told, it's not unusual for a simple heuristic evaluation process to take from a few days to a week or so, or a bit longer if the product/service is more complex.

Review teams typically involve practitioners from a variety of perspectives, for example, a UX researcher (who may have expertise regarding the target audiences), a UX designer (with knowledge of interaction design), a visual designer (with experience crafting graphics and visual aesthetics), and/or a developer (with knowledge of any coding, programming, hosting, or technical environments relevant to the product/service).

Technical Discovery Meeting

If a product or service includes digital or technical deployment, it is helpful to have a meeting or series of meetings early in the design process to examine and discuss any relevant technologies that will or may be involved in achieving success. For websites and mobile applications, this often involves identifying which coding and programming languages will be utilized, which hosting and content management systems are (or are not) in use, and whether the project activities will involve designing for currently available in-house or out-of-house systems—or the selection of new ones. In other words, the team "talks tech" and identifies what technological limitations and opportunities exist in relation to this new or evolving product.

Technical discovery helps to contribute to the apolitical nature of human-centered design processes, as it brings technical parameters to light early in the process in a neutral way. (You'd hate to discover after months of work that you've been designing for the wrong digital deployment platform or that you need to buy a whole new one.)

The goal in a technical discovery meeting is to identify the realities of product deployment without letting technical limitations unduly corral creativity. Discussions related to digital products often include any existing digital ecosystem, data sources, third-party services, and related applications in play. Identifying what is known or needs to be known about the technical milieu the product will be in allows the team to take those into account as interaction and interface designs come together.

As a bit of a digression: an ancillary benefit of a systematic human-centered design process is that you can define your programmatic goals irrespective of technical limitations, at least at first, ensuring that you capture a vision that is reasonably unbounded by technical limitations, as a means of fostering creativity among the project team. In other words, it's helpful to define up front what you hope and intend to accomplish before letting technology box you in. Otherwise you always end up designing for yesterday, rather than today and beyond.

Anything envisioned will ultimately be bound by the capabilities and technologies of today, but I've found that articulating what you hope to accomplish, rather than what your system allows you to do, helps teams (developers very much included) to innovate around what is possible today and think creatively about what they may accomplish tomorrow. While the province of a technical discovery meeting (or meetings) is largely what development-related factors are in play today, if prior discovery activities have given the project team a rough approximation of where they'd like their product to go, this can be a good time to start balancing what is proposed against what digital/non-digital systemic supports and boundaries exist.

This discussion can also help organizational leadership to talk openly with development team experts to understand the distinctions between what is technically impossible, what is technically difficult, and where organizational priorities may need to be realigned in order to meet blue-sky product goals.

Fundamentally, the outcomes of the technical discovery process will be an articulated understanding, often documented, of what systemic factors may impact or guide the instantiation of the product/service in question.

Content Audits and Content Strategy

If the product will include information presented to users in the form of text, such as website content, it is expeditious to review existing content, proposed content, and to catalog it in a manner that enables easy overviews and summary assessments of what content exists, what needs to be generated, who owns it, who will generate it, where it lives at the moment, whether it will be retained moving forward, whether it needs edits and what type, where it sits in a migration cue, and where it will live in the finished application, system, or website. A spreadsheet with this information can prove invaluable at helping teams move quickly through content evaluation, generation, and deployment steps.

Gathering this information is typically accomplished through a content audit. As strategies come together around the purpose (or repurposing) of content, content strategists typically work towards the creation of comprehensive rationales and guidance regarding how and where content is to be utilized, all of which is codified in content templates and content strategy guidance documents (essentially style guides for content).

Personas and Journey Maps

One of the most important questions a product team can ask and answer is "who are we designing this product for?" To provide specificity to that answer, human factors professionals often create user personas, or fictional summary biographical sketches of core audiences based on aggregated research data pertinent to the product being designed. These sketches put a human face on product design and development practices, and moreover, by including specific evidence-based information drawn from user-needs research and presented as biographical details, they lay the groundwork for technical specifications as the project progresses (Kalbach, 2016; Patton, 2014) (Fig. 8.1).

As a group, a series of personas provides a holistic view of a relevant customer base—what they have in common and most importantly how they differ—all the while highlighting key aspects of core audience's information needs, product use scenarios, and other factors that may be relevant, such as their demographics, experience levels with technology, and more. Once you have identified "who" you are

Fig. 8.1 Sample persona. Source: Courtesy Mad Pow Media Solutions, LLC

talking about, it can be very useful to articulate and document "what they do" and how they interact with systems and processes relevant to your product/service. Such documents may be called journey maps.

Journey maps are documented information about a holistic process, such as how information moves through a system, how users move through a system, or how systems interact to provide a service. They describe an ecosystem at work, often through visual depiction.

For example, imagine a patient talking with his or her physician. The doctor orders a blood test. What steps must the patient go through to comply? Will they need to move to a different building? What paperwork will they encounter? Who will take the blood sample? What happens to the blood after it is taken? What kind of systems does it move through? What types of professionals will it be handled by along the way? Who tests the blood and how? What happens to the test results after they are generated? How does the patient learn about the results? What happens when the system fails? How are the various persons involved in the process trained, updated, and notified as the blood sample moves through the system?

Journey maps enable project teams to understand and agree upon how a system or process currently works and provide a focal point for discussing how a process might be amended to improve it. Journey maps are often presented as visually attractive charts, but any sort of workflow or process-flow diagram can be used. Journey maps are great for understanding and working with complex systems and providing a single point of reference for complex processes. They identify inconsistencies and barriers to interactive experiences, establish a shared visual representation of system interactions for discussion, identify opportunities for streamlining and consolidating processes, and build empathy for those who use or interact with those systems.

Sometimes just reviewing a journey map can lead to insightful realizations. ("Why is that blood vial travelling out of the building and then back into the building later? Couldn't we streamline that process?" "If all these system slowdowns are because the blood sample label creation form is difficult to understand, let's simplify that form!") Journey maps are not only a great way to get an overview of an interaction ecosystem, but they also contribute to an "apolitical" process where everyone involved, regardless of title, responsibility, or background, can agree on the specific "truth" of what is being depicted, and work creatively together to solve what is, then, clearly an opportunity for group innovation, not a vague or badly articulated individual sense that the system "could be better" (Fig. 8.2).

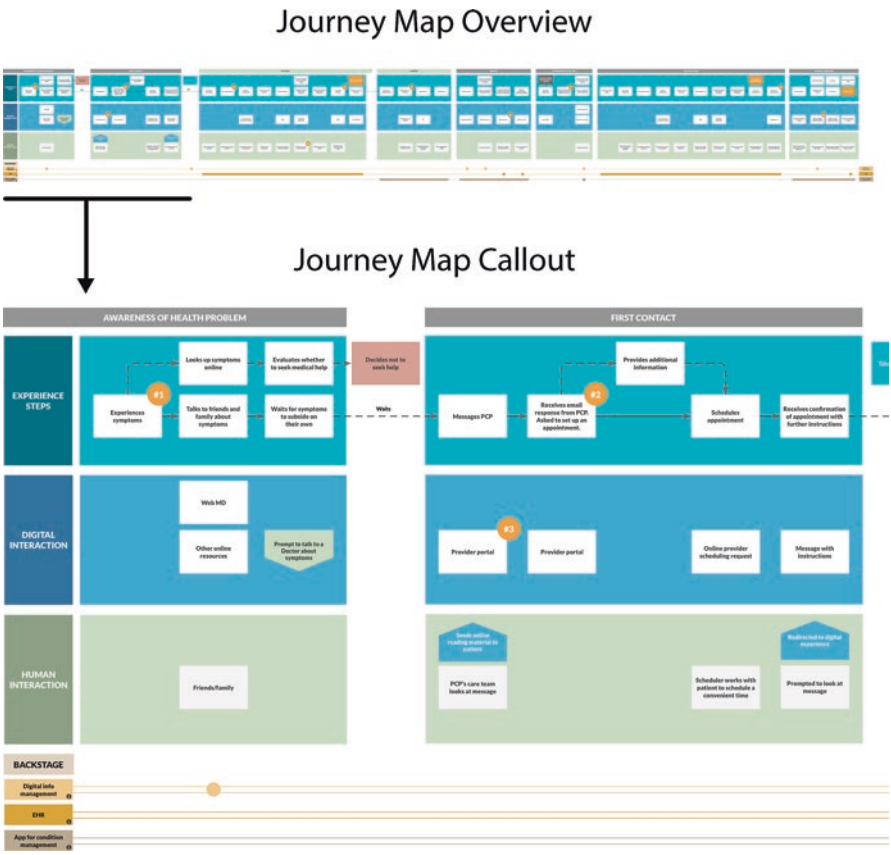

Fig. 8.2 Sample journey map. Source: Courtesy Mad Pow Media Solutions LLC

Sample Content and Interaction Design Phase

In the content and interaction design phase, we begin to put pencil to paper (so to speak) to design our product/service. To support the content strategy and interaction design needs of a project, human-centered design practitioners may utilize the following activities in collaboration with the project team and its partners. While there are a multitude of viable activities that can be part of this process, what follows are some of the most common activities.

Writing Guidelines and Defining Messaging

Content strategists employ a variety of tools to accomplish the generation of fine-tuned and well-written content. These include messaging workshops (defining primary and secondary massages, how they will be delivered, identifying content that

successfully supports information goals, and improving or eliminating content that is off-message), the definition of voice and tone guidelines (defining the "personality" of the content delivered by a product and the "voice" it speaks with, e.g., whether it is casual, funny, serious, or something else), and the creation of an overall messaging strategy to document content-related decisions and guidelines.

Follow-on activities often include content mapping (matching content to screen or display areas), copywriting (crafting textual messages), and Tree Testing (a research activity conducted with users to determine how "findable" key content is in the proposed designs).

Information Architecture

Information architecture is the organizing structure of an interface or the framework through which users interact with a system (Morville, Rosenfeld, & Arango, 2015). For example, a website's information architecture defines not only how content is organized on a page, but how the pages themselves are organized in relation to each other throughout the website.

During this phase activity, user experience specialists define the hierarchy of content and plan its distribution across screens and pages. This often involves defining a comprehensive map or, in website terms, a "site map." Again, in web terms, this shows how every page and unit of content on those pages relate to each other.

Secondarily, information architecture plans not only detail how interface content, navigation elements, and other interface components are taxonomically organized, but in the case of digital products (websites, mobile applications, etc.) they support the definition of how content actually appears on each page or screen, where menus appear, what menu buttons are named, and what webpage each clickable option leads to.

As such, information architecture supports the generation of wireframe documents that define the most basic framework of an interface. To arrive at these deliverables, teams may engage in workflow task analysis, affinity mapping exercises, card sorting, and/or scenario-based collaborative sketching, among other techniques. Information architecture documentation supports the future navigation structure of a product or design. Wireframes typically define key screens or templates for page types (see Fig. 8.3).

Interaction Design

Interaction design activities are where decisions are made about how a product will act, look, and ultimately be organized for presentation to users. Collaborations between product team members and interaction designers through design

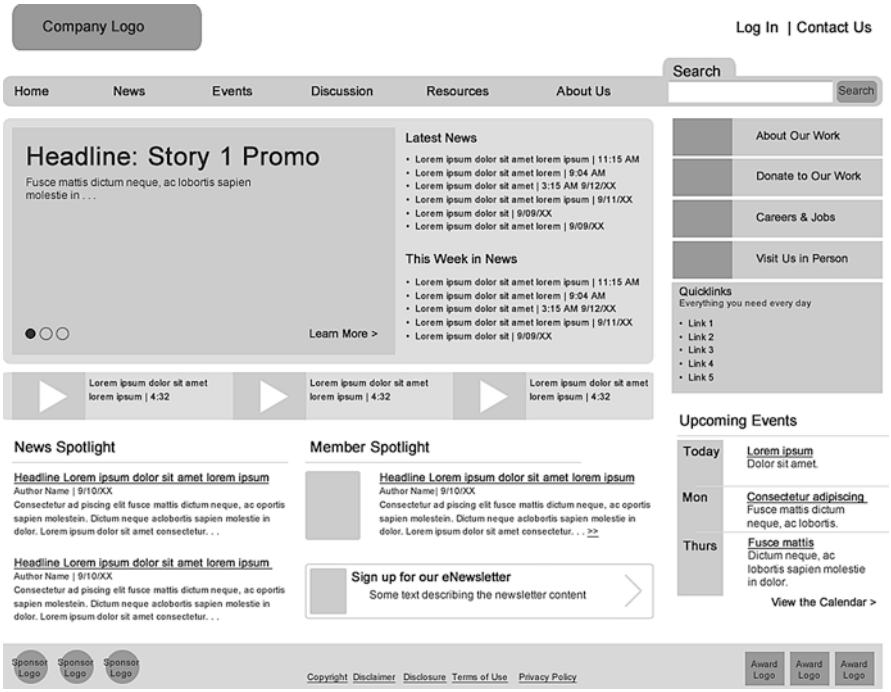

Fig. 8.3 Sample wireframe image. Courtesy: Mad Pow Media Solutions LLC

workshops, wireframing activities, and visual design explorations will at this stage yield representative designs of primary screens, key interaction steps, and creative solutions for how to best serve the information needs of end-users and the business goals of the organization sponsoring the product.

Some interaction design processes, called collaborative design activities, invite end-users (those for whom the product is meant to be used) to participate in the process to add their input as designs evolve. While design teams must be careful not to make end-users designers themselves, their input into the process can be invaluable as sounding boards as solutions emerge.

During this series of activities thoughts and sketches turn into wireframes and ultimately screens to be shared, reviewed, and refined. Care is taken to ensure that information is accessible and that it employs “show don’t tell” approaches that inform and engage.

Visual Design and Branding

As interaction designs come together, at this stage, visual designers typically recommend aesthetic directions for evolving designs in the form of colors, typography, textures, visual effects, and other components that contribute to a desirable visual aesthetic appropriate to the product's purpose and in keeping with any branding guidelines the sponsoring agency may require. These components, along with the components defined in the information architecture activities, are often collected into a component library, sometimes also called a pattern library, comprised of common assets to ensure future scalability of the chosen designs.

Prototyping and Usability Testing

In keeping with the human-centered design tenet of involving users in product design validation activities, often at this stage the project team will create a limited-fidelity prototype that presents the proposed designs in an interactive manner, so that users may simulate product use in an observable manner, and provide feedback regarding how easy to use the designs are, and how they might be improved.

"Limited fidelity" or "low fidelity" simply means providing a simulation of the final product or service that is sufficient to indicate use patterns, without committing the project team to fleshing out the product in its entirety, thus preserving the team's ability to pivot quickly to make improvements. (The more invested an organization is in the production of a product, in general, the less inclined they are to make large adjustments, even if those adjustments are helpful for ensuring a maximally successful product.)

Once created, a prototype can be used in a usability test scenario with end-users simulating product use while a moderator, often a user interaction researcher, moderates and observes in an unbiased manner. It's important to note that a user interaction researcher conducting usability testing will listen to users' feedback, but moreover pay close attention to how the designs support ease of use (or fail to), and it is these observations that frequently provide the greatest insights. People aren't always good at articulating their interactive experiences, so it is vital to pay attention to what they say and do.

It is not uncommon for someone to struggle with a research task and then summarize their experiences with "it wasn't too bad" or "I've seen worse" when an observant moderator might spot a 100 ways an interface might have helped them to succeed more easily, through better layout, typography, nomenclature, navigation structure, accessibility, visual design, or whether or not there is a fundamental mismatch between how users expect a product to work and how it actually does (the cognitive model).

(In one notable instance of a website causing confusion due to the participant's cognitive model (how they thought it should work) and the designer's cognitive model (how the website was organized), a usability test participant I was working with asked how to complete a task she had struggled mightily with. The task she was attempting was to find a specific bit of information on the website. After significant effort, she was unable to locate it. She felt clearly the information should be in a particular section of the website, yet the designers had put the information elsewhere for reasons that she couldn't fathom. When I told her the location of the information she was seeking, she looked up wistfully and said: "Well. Well. Don't that gag a maggot! Why on earth would they that do that?" Shortly after the study had ended, the design team moved the content to the section she (and others in the study) had expected it to be in. Usability testing is awesome.)

Usability testing moderators are typically seeking to capture both qualitative and quantitative data in an unbiased manner. After usability testing, user experience researchers examine the research data collected and draft findings and recommendations for the product team to use to refine their designs.

Supporting the Development Phase

Development processes vary and are directly tied to the nature of the product being created. As such, they are outside the scope of this discussion, but regardless of the type of product, one of the most powerful tools we can bring to bear to for those who build a product is the documentation we generate to bridge the design and development (instantiation) phases.

Effective post-design documentation communicates how key interfaces are organized, what their intended uses are, which components are involved, and where to find them. Design documentation often strikes a positive balance between providing generalizable rules and specific implementation directives through a variety of document types including: interaction guidelines (defining how users interact with the system), branding guidelines (defining how the visual aesthetic adheres to organizational norms), and style guides (defining how components fit together physically and aesthetically).

With these in hand, developers should be able to translate the designs and accompanying graphic files into an instantiated product such as a website, mobile application, or physical device. Inevitably during the course of a project, planned features are phased, some aspects of the product may be de-prioritized for later redesign, or other "next steps" are identified as follow-ons to the primary project work. As questions inevitably arise good communication between design teams and developers is helpful to address emergent concerns and technical limitations that may require design adjustments.

Continued Iteration

Once a product is released or otherwise made available to its user base, it's tempting to think of the product design process as complete. However, the human-centered design process is iterative, and post-release research (benchmark usability testing, user satisfaction surveys, and customer support data) as well as any analytics and metrics available (customer feedback forms, server use data) are invaluable for gauging the success of a product in the "real world" and for identifying and prioritizing opportunities for enhancement. Iterative validations of a product may in effect start a new "discovery" phase that continues, refining the product along the way, through similar activities, with, ideally, each cycle bringing a greater efficiency, efficacy, and satisfaction to the product.

Providing "A Usability"

Having paused, phone in hand, while these thoughts about what it takes to "provide a usability" run through my head, I respond to my corporate caller, assuring him that it shouldn't be too difficult to provide a usability intervention. And, true to form, I ask for additional details including: What is this product for? Who is intended to use it? What will success look like? What is your timeline like?" As we move further into the conversation, I start to attenuate my mental list of human-centered design activities, arranging them into a menu of services that will help this struggling product to succeed. My confidence is high because human centered design processes are transparent, self-validating, and effective— they have never let me down.

One "usability," coming right up!

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Chapter 9
Behavior Change Design: Toward a Vision of Motivational Technology

Dustin DiTommaso

Introduction

During the past 50 years, the developed world has experienced a major shift in the leading causes of illness and death. Chronic illnesses now account for seven in ten deaths in the USA, with heart disease, obesity, cancer, and type 2 diabetes numbering among the most common. As our population ages and as scientific advances continue to transform terminal conditions into ones that people can live with (albeit often uncomfortably), it is likely that these numbers will continue to grow (WHO Global Status Report on Noncommunicable Diseases, 2014).

Thankfully, these diseases can be successfully managed or prevented in part by engaging in lifestyle behaviors such as maintaining a healthy diet, abstaining from tobacco use, drinking less, exercising regularly, and when necessary taking medication as prescribed. However, despite proven, widely known methods to alleviate some of the most deadly, burdensome, and costly chronic conditions of our time, millions of people struggle every day to do what is objectively good for them. Why is this?

Initiating and maintaining healthy behavioral change is a challenging endeavor—both for the individuals who are attempting to make changes and for the myriad of practitioners providing support and guidance along their journey. Health behaviors and behavior change processes are complex, involving a web of personal, interpersonal, and environmental factors that influence our decisions and abilities to behave in certain ways. Changing behavior requires juggling multiple and often competing motives. It may require developing new skills and making fundamental shifts in how one orients to the social and physical environment around them. Complicating

D. DiTommaso (✉)
Mad*Pow, Boston, MA, USA

Rhode Island School of Design, Providence, RI, USA
e-mail: dustin@madpow.com

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things further, problematic health behaviors tend to co-occur (*e.g.*, people who smoke or have poor dietary habits tend to be less physically active) and certain conditions may require changing multiple behavioral patterns (*e.g.*, weight loss efforts often focus on level of physical activity as well as dietary intake, both the amount and kinds of food eaten).

Finally, it is clear that most attempts to facilitate behavior change at individual, organizational, community, or population levels are executed via implicit commonsense models of behavior and behavior change rather than through a systematic application of theory, evidence, and technique. Effect sizes from commonsense interventions trend toward minimal at best, particularly when delivered through digital means such as websites and native mobile applications.

Guidance from the Medical Research Council (MRC) Population Health Sciences Research Network (PHSRN) states that "best practice is to develop interventions systematically, using the best available evidence and appropriate theory" (Craig et al., 2008) but intervention designers and researchers need practical frameworks and methods to effectively bring theory and evidence into the fold. This chapter will outline one such process and highlight frameworks to strengthen the design, implementation, and evaluation of behavior change interventions.

Toward a Systematic Process of Behavior Change Design

Changing something requires that you first understand it. In the case of behavior change, we need to understand the nature of change at both broad and granular levels regarding specific target behaviors, populations, and the contexts toward which interventions may be applied. For behavior change interventions to be meaningful, they must target behaviors that are clinically significant, address the right determinants that predict target behaviors, and be delivered in a way that fits with the characteristics of the intended recipients, culture, and context.

Maximizing our ability to effect change requires an iterative, systematic process that integrates theory and evidence at every step from problem identification and framing through to solution design, implementation, and evaluation. Ideally, behavior change design methods should form part of a "virtuous spiral" in which empirical evidence is used to create an ever-improving design methodology that is applied to improve human well-being and whereby rigorous implementation insights feed back into the advancement of behavior change science.

What Is Behavior and How Does It Change?

"Behavior" can be defined as "anything a person does in response to internal or external events" (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). Many individual behaviors are recurring and can be described as "behavior patterns" and

characterized in terms of their frequency, intensity, and duration over a period of time. Smoking, overeating, physical inactivity, and staying up late are all examples of health-related behavior patterns. Behaviors are part of an integrated system such that any one behavior can be influenced by other behaviors of the same or other individuals as well as environmental affordances. These influences are dynamic and interact both positively and negatively with each other, and their relationships can change over time.

Behavior can be said to have changed when (1) activities in a particular context are undertaken differently from how they would normally have been performed; and (2) when the incidence of one or more activities that individuals, groups, or populations is different than it had been previously. In either case, the change may be maintained over a period of time or the behavior may revert to its original pattern. In most cases, for behaviors to translate meaningfully into improved population health, they must be sustained over the long term. It is important to note that the underlying factors influencing initiation and maintenance of behavior change may be different, and our strategies to facilitate change may need to be tailored accordingly.

Frameworks for Understanding Behavior and Behavior Change

Behavioral science is advancing rapidly, and there are many theories of behavior and behavior change that aim to explain and predict when, why, and how behavior change occurs (or does not occur). Designing or selecting effective strategies for behavior change needs to be based on a clear understanding of which behaviors are likely to be the easiest to change and deliver the greatest impact, as well as what the underlying individual, interpersonal, and environmental barriers and facilitators to the selected target behaviors may be.

Gathering evidence for a "behavioral diagnosis" is often conducted through systematic reviews of the scientific literature, in-depth interviews or surveys with domain or subject matter experts, target population groups and other stakeholders, or less formally through collaborative workshop activities with above groups. A critical step between understanding behavior in context and linking it to theoretically grounded behavior change techniques is to identify precisely what needs to change in the person or the environment in order for the desired change in behavior to occur. The more accurate our analysis of identified target behavior and underlying determinant, the more likely our intervention will be to change behavior in a desired direction.

To do this successfully, we can leverage the COM-B model of behavior, developed by Susan Michie and colleagues at University College London's Centre for Behaviour Change. COM-B stands for "Capability," "Opportunity," "Motivation," and "Behavior" and is a composite behavioral model built from a synthesis of overlapping behavioral determinants found across 93 different theories of behavior and 19 frameworks for behavior change (Michie et al., 2013; see Fig. 9.1).

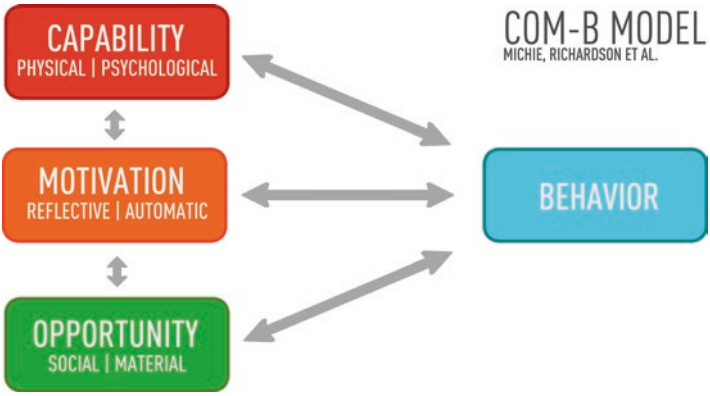

Fig. 9.1 The Capability Opportunity Motivation Behavior Model (CM-B). Source: Original graphic by author, based on Michie et al. (2013). Used with permission

The COM-B model of behavior posits that for any given behavior to occur, a person must have the capability and opportunity to execute the behavior, and that the motivation to engage in a given behavior must be greater than to engage in any other potentially competing behavior/s. For example, in the moment at which you planned to go for an after work run, your co-workers invite you to the pub across the street for hot wings and pints.

Each of the model's C, O, M components can be divided into two types.

Capability includes both "physical" and "psychological" capability. Physical capability consists of having sufficient strength, stamina, dexterity, or physical skills needed to enact a behavior. Psychological capability refers to knowledge and cognitive skills as well as our perception, attention, memory, decision processes, and abilities to regulate our behavior.

Opportunity consists of the surrounding environmental factors that restrict or enable a behavior. These may be "physical" in terms of time, triggers, resources, physical location barriers, or "social," including cultural norms, interpersonal influences, and social cues.

Motivation refers to all the mental processes that energize and direct behavior. This includes conscious, "reflective" processes such as goals, intentions, plans, values, and beliefs as well as "automatic" processes involving our emotional and habitual responses, desires, attitudes, and impulses.

The COM-B model also reflects the interactions between the different components, with motivation playing a central role. Increased motivation can energize people to engage in activities that will increase their capability (*e.g.,* practicing new skills) or opportunity (*e.g.,* we respond to more cues when we are strongly motivated), thereby facilitating behavior change. In addition, increasing opportunity or capability can increase motivation (*e.g.,* we like to do things we are good at and have the opportunity to do).

We can think of these interactions in terms of riding a bicycle (as a target behavior). If we own a bicycle (opportunity), and are able to ride it (capability), it might increase our motivation to ride a bicycle but our motivation alone will not improve our riding skills or provide access to a bicycle unless we act (behavior) on this motivation and buy a bike and/or practice riding.

Changing behavior therefore requires change in one or more of capability, motivation, and opportunity, and these factors serve as targets for behavior change techniques and interventions overall (Abraham, Kelly, West, & Michie, 2009).

Behavior Change Design Process

Behavior change design is a systematic approach to design, integrating methods and principles from behavioral science, motivational psychology, and human-centered design. The process is iterative and sequential combining the rigor of behavioral science with the creative ingenuity of human-centered design. At its core, designing for change is the process of defining a real-world problem, understanding the needs, contexts, and change targets of affected and at-risk populations, creating the elements of an intervention to shift those targets, and refining those elements through a series of studies (Fig. 9.2).

We broadly describe this process as a series of four phases:

1. Diagnosis—where we seek to understand and define a problem, a target population and targets for change,

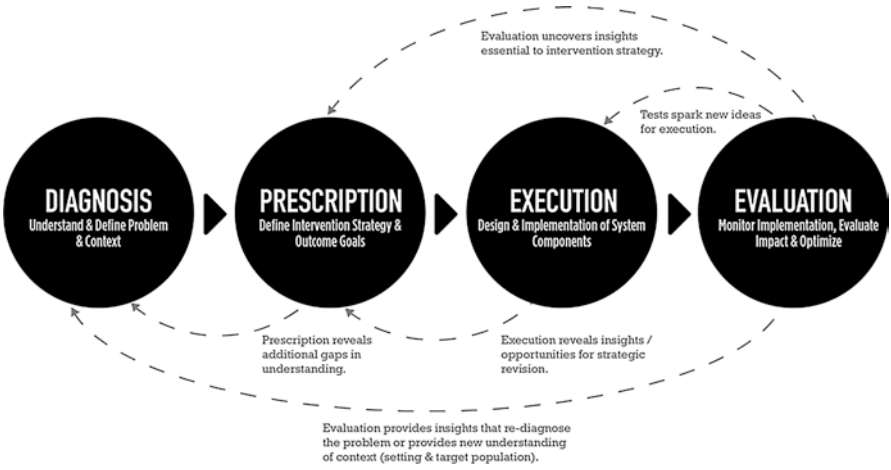

Fig. 9.2 Behavior change design methodology. Source: Mad*Pow. Used with permission

2. Prescription—where we detail the precise mechanics for how the intervention will function, what techniques will be used to change what behaviors through which mechanisms of action (mediators), and how those techniques will be delivered (*e.g.,* digitally, face-to-face, and environmental change),
3. Execution—where we translate the intervention strategy into content, artifacts, interface, and interactions, and.
4. Evaluation—where we perform as series of studies throughout the design process to assess the intervention for conceptual clarity, usability, utility, acceptability, feasibility, efficacy, and effectiveness. It should be noted that the process is not strictly linear, with evaluation activities occurring throughout the process and earlier phases being returned to as needed.

Phase 1: Diagnosis

Understand and Define the Problem

As we have said, changing something requires that you first understand it. At the start of any project, we seek to understand the individual, interpersonal, and environmental factors that give rise to (or sustain) a problem over time, who is affected (or at risk of being affected) by the problem and how risk or protective factors and experiential contexts may vary across populations.

This involves conducting a variety of qualitative and quantitative research activities: analyzing available data sets, conducting systematic evidence-based literature reviews of interventions in a given space, using survey instruments, and conducting in-depth interviews with our target audience, stakeholders, and relevant subject matter experts. Taking a mixed-methods approach to diagnosing a problem allows us to unify several sources of information into hard-nosed, empirical data about a problem space, including the interventions that have been deployed to effect change, their underlying theoretical basis and evidence about what has worked (and not worked) for whom, in what contexts, and first-hand accounts of the stated needs, mindsets, and lived experiences of our intended intervention beneficiaries.

Once team members have a solid understanding of the shape, complexities, and root causes of a problem, decisions can then be made on where to intervene to bring about change. Often, graphic representations of a problem illustrating relationships and causal pathways are used to help inform decision-making. These diagrams can take the shape of path charts, logic models, or structural equation models linking the problem statement to macro- and micro-level factors that contribute to the problem and desired distal and proximal outcomes. These outcomes must be measurable, and benchmarks are often laid out as thresholds for success.

Specify the Target Behavior/s

With a model of the problem and desired long- and short-term outcomes constructed, the next step in designing a behavior change intervention is to identify which behaviors are likely to deliver the greatest impact and can be most easily changed. This is achieved through conducting a "behavioral diagnosis" which describes as precisely as possible who needs to what differently, when, where, how, and with whom (if applicable). The more precise you can be about the behavior, the better the diagnosis is likely to be.

For example, if addressing obesity, one might suggest that overweight individuals reduce fat and sugar consumption by packing vegetable snacks in their lunches rather than cookies or sweets and that sugary beverages be substituted with water or (sugar-free) teas, or that meals be planned in advance, grocery lists made, and nutrition labels read before making food purchases. These categories of behavior—shopping, meal preparation, and eating— could be performed by different people (e.g., a family member or housemate could be responsible for the shopping and meal preparation rather than the overweight individual and would need to be engaged in the intervention).

Additionally, we could decide to target supermarket managers to change product placement on shelves (e.g., placing lower fat or sugar products up at eye level and / or making high fat/sugar foods harder to find, or running promotions on healthy foods) or even government policy makers to change the way nutritional information is displayed on food labels, or introduce regulations on advertising or taxes or size limits on sugary beverages.

Our objective here is to ensure that our behavioral diagnosis is sufficiently detailed and useful (e.g., "eating less" is less likely to be useful than "overweight individuals substitute veggie snacks for sugary snacks in their lunchboxes") and to define the target population (who is to take action), the nature of the behavior (what they will do), and the context of the behavior (how and when they will do it), and the setting of the behavior (where will it be performed).

Only when these details are pinned down, can we then analyze barriers and facilitators to performing the target behavior/s and what exactly needs to change in people and/or the environment to bring about behavior change (Francis, O'Connor, & Curran, 2012; Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011). We do this through a "COM-B Analysis."

Identify What Needs to Be Changed

As described earlier, changing behaviors requires changing the individual, interpersonal, and environmental determinants that underpin selected target behaviors. To accomplish this change, we analyze and map these determinants to individual capability (psychological and physical), motivation (reflective and automatic), and environmental (social and physical) as outlined the COM-B model in Fig. 9.1 and Table 9.1.

Table 9.1 COM-B component definitions and examples

COM-B component definitions	Examples
Psychological capability Awareness, attention, memory, knowledge or mental skills needed to engage in a behavior	Understanding the effects of consuming carbohydrates has on one's blood glucose
Physical capability Physical skill, strength, dexterity, or stamina needed to perform a behavior	Having the skill to take a blood sample for a glucose check
Reflective motivation Deliberative, conscious processes involving plans, intentions, and evaluations (beliefs about what is good and bad)	Having a goal to quit smoking
Automatic motivation Fast, automatic processes involving emotional reactions, attitudes, habits, and basic needs (physical, psychological, social)	Feeling anticipated pleasure at the prospect of eating a piece of chocolate cake
Physical opportunity Opportunity afforded or constrained by the physical environment involving time, resources, locations, cues, built or natural "affordances" (e.g., safe running path)	Being able to go running because one owns an appropriate pair of running shoes
Social opportunity Opportunity afforded by interpersonal influences, social cues, and cultural norms that influence the way that we think about things and our subsequent behaviors	Being able to smoke in the house of someone who also smokes but not inside a restaurant, bar, or office

Source: Derived from Michie et al. (2013). Used with permission

An effective COM-B analysis draws from different sources. COM-B questionnaires are created to uncover target audience, subject matter experts, and stakeholder perspectives on barriers and facilitators underpinning the selected target behaviors, and coding and quantifying the evidence gathered from the scientific literature review. By mapping underlying determinants to each target behavior, teams can identify prominent barriers that need to be addressed through intervention design. Specifically, by focusing on which COM-B factors might be malleable through design and targeting them with behavior change techniques most likely to shift an individual's capability, motivation, or opportunity into a new equilibrium.

At the end of the diagnosis phase, intervention design teams should have robust conceptualization of the causal arguments that produce and sustain a problem, desired behavioral, proximal, and distal outcomes and modifiable determinants that mediate behavior change for differing populations. The importance of devoting sufficient time and resources to the diagnosis phase of a project cannot be overstated. If the diagnosis is not thorough, the formulation of the problem and identification of effective change targets is less likely to be accurate, and the intervention is much less likely to be effective.

Phase 2: Prescription

Having completed a thorough diagnosis, design teams can now consider what intervention strategies are most likely to be effective in altering the relevant mechanisms of change.

Currently, "The Behaviour Change Wheel" (Michie et al., 2011; Michie et al., 2014) outlines nine broad strategies (or "functions") by which an intervention can change behavior and links them to COM-B components. We've added a 10th ("Needs Satisfaction") to draw more deeply upon motivational change mechanisms outlined in Self-Determination Theory (Ryan & Deci, 2011).

The ten intervention functions are:

1. *Education* (i.e., increasing awareness, knowledge or understanding),
2. *Training* (i.e., developing mental or physical skills),
3. *Persuasion* (i.e., using communication or design tactics to change attitudes or beliefs toward a target behavior, induce positive or negative emotions, or stimulate action),
4. *Incentivization* (i.e., setting the expectation of financial or other rewards),
5. *Coercion* (i.e., setting the expectation of punishment, cost, or personal loss),
6. *Needs satisfaction* (i.e., creating experiences that satisfy inherent basic psychological needs for autonomy, competence, and relatedness),
7. *Restriction* (i.e., using rules to reduce the opportunity to engage in a target behavior),
8. *Environmental restructuring* (i.e., changing the physical or social environment),
9. *Modeling* (i.e., providing a visible example for people to imitate or aspire to), and.
10. *Enablement* (i.e., increasing means/reducing barriers to capability beyond education and training or increasing opportunity beyond environmental restructuring).

For example, if our goal were to increase medication adherence in individuals with hypertension, our COM-B analysis may highlight reflective motivation (e.g., beliefs about necessity for medication, beliefs about effects/side-effects of medication, lack of intentions to medicate as prescribed) as an important factor to be targeted via intervention. We can then craft our strategy around a number of relevant functions to change motivation such as needs satisfaction, persuasion, incentivization, education, and/or modeling.

Intervention functions can be delivered by a number of "behavior change techniques" (BCTs). BCTs are "the smallest active ingredients of an intervention, hypothesized to change behavior" (Michie et al., 2013, 2015). 93 techniques have been identified and organized into a taxonomy— the "Behavior Change Techniques Taxonomy v1 (BCTTv1)"—allowing for a systematic method to identify what are likely to be the most appropriate techniques for a target behavior, barriers, population segment, and setting.

While BCTs have been reliably linked to intervention functions, evidence continues to accumulate regarding the effectiveness of different behavior change

techniques as applied to different target behaviors, populations, and settings, such as increasing physical activity among healthy versus overweight, obese and older adults (Olander et al., 2013; Olander, Berg, McCourt, Carlstroem, & Dencker, 2015) or techniques delivered via different modalities like face-to-face, telephonic, text message, or in-app content. Further research has suggested that interventions that use more behavior change techniques (mean no. of techniques = 8.57) are more effective than those that use fewer techniques (mean no. of techniques = <4) (Gardner, Smith, Lorencatto, Hamer, & Biddle, 2016; Webb, Joseph, Yardley, & Michie, 2010).

Finally, some evidence exists that suggest behavior change techniques may produce greater effects if they are delivered in theoretically informed groups rather than in isolation. A common and effective pattern that can be found in countless digital applications stems from Control Theory (Carver & Scheier, 1982) and pairs goal-setting, action planning, self-monitoring, and feedback (Dombrowski et al., 2012; Michie, Abraham, Whittington, McAteer, & Gupta, 2009).

Whether an intervention is to be specified at the individual, organization, community, or policy level, the processes outlined in diagnosis and prescription phases provide a methodology for adequately defining a problem space, identifying the malleable determinants that lead to change and articulating the logic of the intervention. With an emergent strategy in hand, teams can begin to translate the prescription into intervention artifacts such as content, activities, interfaces, and interactions, which is the focus of the next phase.

Engagement: The Other "E"

Beyond prescribing the "active ingredients" that mediate change, we also want to focus our efforts on strategies that have been shown or hypothesized to support engagement with digital applications. We see engagement as the other critical consideration in designing for behavior change.

Much of the rationale behind engagement design decisions comes from principles embedded within Self-Determination Theory (Ryan & Deci, 2011). According to SDT research, we humans have basic (universal) psychological needs that we need to fulfill in order to thrive, and that we seek out and continue to engage in experiences that satisfy these needs. These needs are:

Competence, which is our need to feel effective and capable of doing things well. It's the feeling we get after attaining a challenging goal and the experience of mastery when our competence for a particular task or goal is supported consistently.

Autonomy is our need to experience our actions as our own. To wholeheartedly endorse what we're doing at the time we're doing it. It's the feeling we get when we act with a sense of purpose and choice.

Relatedness is our need to feel cared about by the people we care about. It's the feeling of belonging, like we're understood and can be ourselves around people who "get" us.

These needs can be fulfilled via digital technologies through the way we communicate with end-users and the interactions we provide. Unlike finding just the right context specific and often individually tailored pairings of BCTs to shift behavioral determinants, SDT techniques for satisfying basic needs and facilitating engagement are applied in all designs, for all users, in all contexts. Our goal is to make every user feel competent, in control and cared for.

Supporting Basic Psychological Needs

SDT and its concept of needs satisfaction is an excellent framework for designing any interactions—so much so, it's shocking that it isn't used more in the design world. Here, we'll look at a few principles that are universally applied in our version of behavior change design.

Supporting Competence

The cornerstones of supporting competence are built from (1) meeting people where they are in terms of their mental and physical skills and abilities; and (2) providing structure (e.g., actions, tools, and resources) and informationally rich, supportive feedback on performance, and progress to help them hone the skills they need to address challenges.

It is now overwhelmingly clear that one-size-fits all approaches to intervention design are far from ideal. People start with very different knowledge and skills to carry out behaviors. They have different strengths to capitalize upon and different challenges to overcome. Enabling individuals to select specific and challenging enough proximal goals and a reasonable way to achieve them helps them to stretch and develop their skills without feeling completely overwhelmed. These "optimal challenges" lead to experiences of mastery and sustained engagement critical in behavior change pursuits.

Supporting Autonomy

Part of autonomy support is helping individuals develop personally relevant and meaningful behavioral goals, as people will have the most energy and interest for activities they like to do and that they personally value. Allowing individuals to explore bigger-picture life goals and how behavioral goals fit into their higher-order

motives helps to energize and sustain motivation toward behavior change goals and desired outcomes.

For many, if not most health outcome goals, there might be different ways by which individuals may strive to achieve them. For example, controlling high-blood pressure may be achieved through medication and/or lifestyle changes such as increasing physical activity and changing one's diet. Within each method there could be additional choices offered such as type of medication, activity (e.g., jogging, swimming, etc.), or dietary changes (increased potassium, salt-reduction, DASH diet, etc.).

Providing options for what goals to pursue and how to pursue them when possible, strengthens our sense of choice, and endorsement. Finally, when choice is constrained or not possible, providing a meaningful rationale for why that is helps individuals accept the limitations without sacrificing their autonomy.

Supporting Relatedness

Attempting to assist any individual with their own behavior change requires that they trust you, that they feel you have their best interests at heart, and that you will be there for them when needed regardless of their abilities, decisions, progress, or lack-thereof. Meeting this requirement starts by offering an environment of warmth, respect, empathy, and compassion.

Understand that individuals may have different reasons for making changes and they might also have different feelings about those reasons, including negative or ambivalent ones. Instead of assuming every user is super gung-ho and always ready for action, acknowledge that they might get annoyed or frustrated on their journey and that it is a normal and acceptable part of the process. And speaking of being annoyed, when presenting (options of) actions a user might take, make it a request not a demand. Steering clear of "musts," "have to's," and "shoulds" is not only more polite, it's more motivating in the long run.

Additionally, we should think about relatedness and relationships outside of the immediate context of the interventions. Sometimes, when making changes even with the best digital support, people need some real-world human support as well. Designing in opportunities to connect users with their real-world support teams, and potentially coaching them on how to seek support when needed can strengthen a person's sense of relatedness.

Finally, creating safe digital spaces for people making similar changes to connect, learn from each other, and provide each other support and encouragement can be a powerful engagement mechanism for digital interventions.

Whether an intervention is to be specified at the individual, organization, community, or policy level, the processes outlined in diagnosis and prescription phases provide a methodology for adequately defining a problem space, identifying the malleable determinants that lead to change and articulating the logic of the intervention. With an emergent strategy for engagement and effectiveness, teams can begin

to translate the prescription into intervention artifacts such as content, activities, interfaces, and interactions, which is the focus of the next phase.

Phase 3: Execution

Where we previously mentioned that the design process as a whole was an iterative process, the execution phase is perhaps by nature the most iterative. It is here where broader design teams—interaction design, content/copy writing, visual design and branding, coding, and UX research— come together with intervention designers to visualize and evaluate the evidence-based strategy developed in phases 1 and 2. This collaborative process typically involves multiple rounds of ever increasing fidelity, depth, and precision from initial concept development, through prototype revisions, to minimum credible pilot intervention and implementation ready intervention.

In line with modern human-centered design approaches, it's important that the "end-user" is involved during the creation process. This can take shape through co-design workshop sessions, often held as part of pre-concept and concept development workstreams and evaluation sessions, where feedback on the intervention is sought from our intended beneficiaries. As described in the diagnosis phases, designing for behavior change involves a balanced integration of theory, evidence, and the perspectives of the people who will use the intervention.

Our end-goal in behavior change design is that we've been effective and our efforts meaningfully change behavior. Getting there requires that the intervention also be useful, usable, attractive, engaging, trustworthy, valuable, and not overly burdensome to our users. It's critical that the tone, features, and functionality fit the needs, understanding, and preferences and we avoid or modify as much as possible the elements that are not easily understood, disliked, or seen as impractical or intrusive.

We believe that designing with people and including their perspectives—rather than deploying interventions that seek to capitalize on perceived human shortcomings, manipulate or otherwise trick into behaving even in certain objectively beneficial ways—reduces the potentially inherent paternalism of designing for other people's change, preserves their autonomy, and ultimately delivers a better product, service, or intervention.

Phase 4: Evaluation

As a workstream, evaluation runs in synchronicity with execution phase activities. The focus of early tests is on seeking direction, refining and confirming design iterations (in order to produce more acceptable, useful, and effective interventions). Ultimately, evidence will need to be gathered to assess whether the intervention is producing the kind of effects it was intended to and if there are any side-effects or unintended consequences.

Typically, this is done through a sequence of tests beginning with a small pilot test of a minimum credible intervention to revise and scale the intervention, then a higher fidelity and larger scale efficacy test under tightly controlled conditions, and finally an effectiveness test of an appropriately scaled intervention "in the wild."

The Logic of Experimentation

During intervention research, we often decide between two basic types of research designs: experimental and quasi-experimental designs. Experimental designs such as A/B tests and Randomized Controlled Trials (RCTs) use random assignment to create intervention and control groups, meaning sample of your population is exposed to the intervention you want to test and the other receives treatment as usual, a different intervention, no treatment or waitlist.

When randomization on a large enough sample size is used, post-intervention differences between groups can be considered causally related to the intervention (assuming no contamination or spillover occurs). No other method of group assignment or statistical adjustment produces similar effects.

Quasi-experimental designs have the same goals and structural features of experimental designs except instead of random assignment, participants are allocated into groups (if there are more than one) by nonrandom means such as self-selection/enrollment or researcher assignment/enrollment. By using nonrandom assignment, quasi-experimental designs are exposed to a variety of potential biases or "selection effects."

For example, participants self-selected to receive an intervention may be more motivated to change behavior than participants who do not volunteer, skewing effects. It then becomes the researcher's job to rule out potential alternative explanations for effects. This can be done effectively through taking multiple measurements over a period of time, called interrupted time-series design, as opposed to more common pre-post measurement designs.

Pilot Testing

As stated above, intervention design is a systematic and iterative process that begins with identifying and understanding a real-world problem to inform the design of an intervention, progresses through pilot evaluation to testing impact, and may include optimization or adaptation efforts after release.

Pilot testing is typically performed after concept and prototyping phases, when an implementable minimum credible intervention is developed. The goals of pilot testing are to (1) refine the intervention based on its usage and performance by its intended audience, in its intended setting, and (2) to collect preliminary evidence of change in mediators (COM-B factors), target behaviors, and proximal outcomes. The design of pilot tests is nearly always quasi-experimental. It generally involves a single group of participants who are aware that they are

part of a pilot test (and may be asked to provide feedback on the intervention as part of the study).

As such, pilot testing requires both quantitative and qualitative measurement. Data collection and analyses focus on understanding participant experiences and responses to the mechanics, materials, and content of the intervention, including their level of engagement, satisfaction, and if the intervention seems to produce change in mediators.

Efficacy Testing

After an intervention has been designed and pilot tested, we want to know whether it works. Specifically, based on the intervention design strategy, does the intervention produce change in the mediating variables, and do the changes in the mediators appear to produce changes in behavior and proximal outcomes?

Efficacy tests involve random assignment of participants to intervention conditions and control groups, or they may utilize more rigorous quasi-experimental methods such as "regression discontinuity designs," where participants are measured on a key indicator and the intervention is only offered to those participants who reach a certain threshold level on the measure. The difference in regression lines (intercepts and slopes) between the two groups can provide evidence for intervention effects.

While the intervention can be revised based on findings from the efficacy tests, a complete, high-fidelity, stable release of the intervention is important for an efficacy test. Technical difficulties, incomplete content, or low-quality execution will all confuse the results.

Finally, inclusion and exclusion criteria are often used to screen participants to ensure they represent the target audience.

Effectiveness Testing

In public health and social work, effectiveness is required for program and intervention adoption. In the commercial world, digital products, technologies, and interventions are much less likely to be rigorously evaluated for impact before (or even after) wide scale release. In our experience, measures that appear to be of greater concern include speed to market, reach, adoption, engagement, conversion, and revenue.

That said, as digital tools for assessing, monitoring, and managing our health continue to proliferate an already saturated market, we believe the fight for consumer dollars will be based on effectiveness. A key differentiator in purchase and use will be if the solution delivers its intended (or claimed) effects. Organizations that build a practice of rigorous research, design and evaluation methods now, will be ahead of the game as the gravitational shift toward effectiveness comes to fruition.

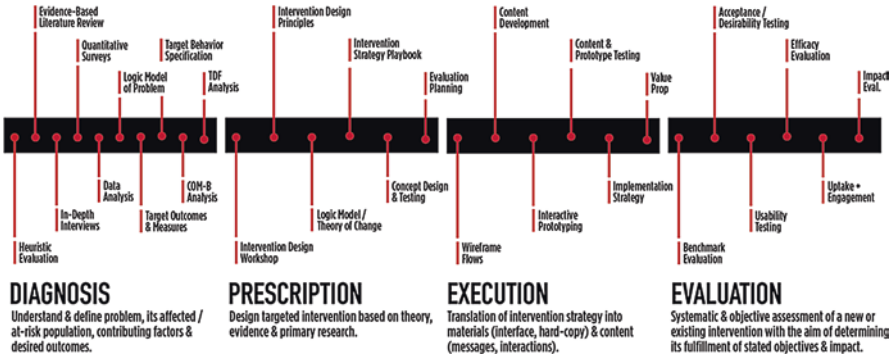

Fig. 9.3 Common design activities undertaken throughout an intervention design process. Source: Mad*Pow. Used by permission

Whether for necessity, differentiation, or contributions to science, the goal of effectiveness testing is to estimate the impact of an intervention under real-world conditions, compared to "status quo" treatment or another active intervention. In other words, a new intervention that has been shown to achieve the desired outcomes under the ideal conditions of an efficacy test is now exposed to other settings that represent the variability of conditions for which the intervention was intended. Unlike efficacy tests, the two conditions are relaxed in an effectiveness test, and the usage (uptake and engagement) of the intervention is subject to natural variation.

When introducing more relaxed controls, it is likely that trade-offs have to be made with our confidence that a detectable effect can be attributed to the intervention versus extraneous factors (internal validity) and also to the extent to which the findings can be generalized to other populations or settings of interest (external validity). Best practices here again include combining both experimental and observational methods to come to more confident conclusions.

Depending on the results of effectiveness testing, the intervention may be further rolled out, revised, optimized, or adapted for new settings or populations. It should be noted that interventions rolled out at any scale should be routinely monitored and optimized over time (Fig. 9.3).

Future Directions

The science of behavior change is rapidly advancing and evolving its knowledge base and methods while capitalizing on emerging technologies and advances in other fields such as computer and data science. New opportunities are becoming available to amplify our potential to improve our effectiveness in delivering effective interventions.

Up to the minute knowledge about what works for whom, in what contexts, when and why is being disseminated to intervention researchers and designers. Advances

in computing technology such as contextual sensors, streaming data, and machine learning algorithms are being used to leverage data to predict behaviors and dynamically deliver tailored "just in time" content and techniques. New methods for rapidly evaluating interventions and disseminating findings are being developed in conjunction with technology-based "rapid innovation" methods. New computational model theories that are more in line with our abilities to capture and sense moment-to-moment behavior are being developed to update 50-year-old, "snapshot" style social cognitive models. These are just some of the future directions intervention research and design are headed.

Conclusions

Designing engaging and effective interventions presents both unique challenges and great opportunities. While the promise and anticipation of revolutionary public health impact continues to grow, the industry still remains more in the land of promise than revolution. In order to meaningfully improve the reach, engagement, and effectiveness of digital and offline health interventions, a more rigorous approach to design and evaluation is needed. We argue that a merging of behavioral science and human-centered design methods (and practitioners) with emerging technological advances as outlined in this chapter amplifies all our abilities to deliver on the promise of implementing effective and engaging interventions, to ultimately impact population health and well-being.

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Part III
Consumer-Centered and Consumer-Generated Information

Chapter 10
Consumer Engagement and Empowerment Through Visualization of Consumer-Generated Health Data

Adriana Arcia, Jacqueline A. Merrill, and Suzanne Bakken

Introduction

Information visualization is a term used to refer to techniques ranging from data visualization in which the object is to support exploration of abstract data, to infographics which are used to present information, sometimes in a persuasive way (Cairo, 2012). Information visualizations have been used in a variety of ways to communicate with health care consumers. Examples include pictograms to teach correct medication administration, cartoons to illustrate the "do's and don'ts" of post-discharge wound care, and icon arrays to show the predictive accuracy of a breast cancer screening test (Houts, Doak, Doak, & Loscalzo, 2006; Spiegelhalter, Pearson, & Short, 2011).

The rationale behind the use of visualizations is that they leverage viewers' existing visual analysis skills while reducing the demand on their literacy and numeracy competencies. Indeed, well-designed visualizations have been demonstrated to help narrow the comprehension gap between individuals with low and high levels of health literacy, and between native and non-native speakers of the target language (Garcia-Retamero, Okan, & Cokely, 2012).

The focus of this chapter will be on the method we have developed to create infographics tailored for the individual health care consumer using data they generate. The resulting tailored infographics are intended to support comprehension as well as engage and empower the viewer. In this chapter, we will cover the five steps

A. Arcia (✉)
School of Nursing, Columbia University, New York, NY, USA
e-mail: aa2594@columbia.edu

J. A. Merrill · S. Bakken
School of Nursing and Department of Biomedical Informatics, Columbia University, New York, NY, USA

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that make up our information visualization method: (1) defining the intended audience and purpose, (2) understanding the data, (3) iterative design, (4) automation, and (5) evaluation. We developed and refined this method over the course of two projects that will serve as the context for case studies that illustrate these steps.

The first case study context is the *W*ashington Heights/Inwood Informatics *I*nfrastructure for *C*ommunity-Centered Comparative *E*ffectiveness *R*esearch (WICER) Project.[1] The purpose of WICER was to gain an understanding of the health of the local community in which Columbia University Medical Center is located. Central to this effort was a survey of over 5800 community residents in which we collected self-reported measures on topics such as nutrition, mental health, health literacy, physical activity, and overall health, in addition to height, weight, waist circumference, and blood pressure. The impetus for our work in information visualization began with the need to return WICER data to the participants in a way that they would find easily comprehensible and actionable in the context of generally low levels of health literacy. Our solution to this communication challenge was to develop infographics of the WICER variables that are then tailored with the data of the individual participant.

The second case study context is the *N*ew York City *Hi*spanic Dementia Caregivers *R*esearch *P*rogram (NHiRP).[2] The visualization goal for NHiRP is to support family caregivers of dementia patients in their caregiving and health self-management efforts. Similarly to WICER, the NHiRP infographics are tailored with results from measures of the caregiver's overall health, mental health, and caregiving burden as well as the behavior and stage of dementia of the care recipient. When complete, the infographics will be incorporated into a variety of digital platforms designed to meet the information and communications needs of family caregivers and support them in their self-management.

Intended Audience and Purpose

The first step in our information visualization method is to clearly describe the intended audience and purpose of the visualization. The identification of dissemination format(s) and desired outcome(s) for the visualization should be the logical outgrowths of audience and purpose, respectively. This step is critically important because many subsequent decisions are based on the determinations made at this step.

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[2] Funding provided by the National Institute of Nursing Research (R01NR014430-03S1).

Intended Audience and Dissemination Format

The audience for a visualization will typically have one or more key characteristics in common, perhaps a health condition or care provider, that can be used as the basis for narrowing down the universe of visualization possibilities. Many characteristics may be relevant when defining or characterizing an audience including but not limited to:

- demographics
- educational attainment
- health literacy
- digital literacy
- clinical knowledge/duration of diagnosis
- cultural context
- preferred language
- geography
- preferred media types
- access to technology

Although technically the only common thread for WICER was geographic, residents of Washington Heights/Inwood neighborhoods predominantly have roots in the Dominican Republic so Hispanic ethnicity was a de facto dominant characteristic. Furthermore, based on WICER survey data, we saw that participants were predominantly female, with an average age of about 50, and had a high likelihood of limited health literacy. Based on these characteristics, we determined that we needed to create large-print infographics in both English and Spanish that minimized the demand on reading level and that would be culturally relevant. For example, in an infographic on the amount of physical activity needed to burn off the sugar in a can of soda, we explored the use of city blocks as a culturally meaningful metric for city-dwellers.

Having characterized the WICER audience, we considered the dissemination formats. Due to the need for the infographics to be accessible to WICER participants irrespective of their access to or comfort with technology, we concluded that we needed to be able to print the infographics on paper. As such, all WICER infographics had to be static.

By contrast, the NHiRP visualizations are intended for dissemination digitally and therefore we are exploring the use of interactive features to display information that does not lend itself to a static, single-page infographic format. Considerations for dissemination format include:

- print vs. digital
- static vs. interactive or animated
- size of display (e.g., phone, tablet, desktop, and billboard)
- operating system or platform
- resolution
- accessibility features (i.e., accommodations for disabilities)
- usage setting (e.g., home, clinic waiting room)

Ultimately, the best dissemination format is the one with which the audience is most likely to engage. For some audiences, that may mean choosing the format that imposes the fewest technical requirements, whereas for others it may mean opting for the most eye-catching, cutting-edge technology.

Visualization Purpose and Desired Outcomes

Information visualization can be used to meet a variety of different health communication needs including data exploration/analysis, raising awareness of a health topic, delivering a persuasive message, aiding memorization, or promoting an emotional connection to a topic or entity. For both WICER and NHiRP infographics, their primary purpose is to support comprehension of individual health data. A secondary consideration is the extent to which they motivate the viewer to address the focal health issue. The desired outcomes then relate directly to the stated purpose. For example, a family caregiver who sees an infographic indicating that their self-reported symptoms indicate a high likelihood of psychological distress would ideally comprehend the message, recognize the need to take action, and then carry out self-management actions such as engaging in stress-reduction activities or soliciting professional help.

In our work, we found it useful to approach our infographic designs not by topic, but by the specifics of the comprehension task (Arcia et al., 2016). For instance, for a variable like body mass index (BMI), the comprehension task is to compare a single piece of health information to standard criteria (see Fig. 10.1). The desired outcome is then the identification of that single value and determination of whether it is normal or abnormal. By contrast, for self-rated overall health, chronic stress, or energy levels, the comprehension task could be to compare one's own rating to that of a comparison group (e.g., "other women your age"). Then, the desired outcome would be identification of a value and determination of whether it is lower, the same, or higher than that of the comparison group.

Clearly stating the purpose and desired outcomes of visualization is important because the purpose can point the way toward appropriate graphical formats (e.g., bar chart, icon array, branching diagram, etc.) and the desired outcomes serve as the criteria for eventual evaluation. An information visualization is successful to the extent that it yields the desired outcomes. Therefore, if the purpose of an infographic is to persuade the viewer of the perils of smoking, then it is successful insofar as it prompts smoking cessation behaviors.

Understanding the Data

With the intended audience and purpose defined, the next step in our visualization method is gaining a thorough understanding of the data (see Arcia et al., 2018). The attributes of the variables and datasets to be visualized will necessarily limit the

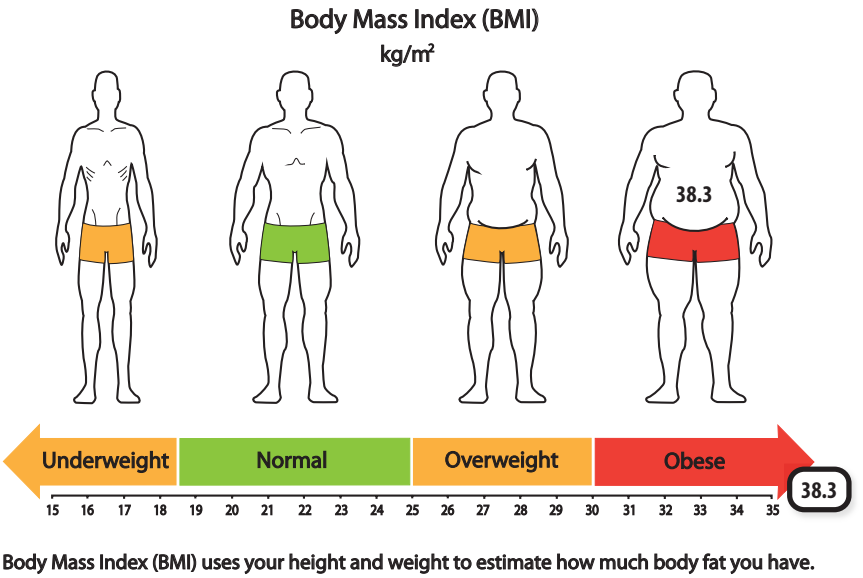

Fig. 10.1 Body mass index (BMI) infographic from WICER showing an out-of-range value (38.3). Initially, we presented the body silhouettes (top portion) and the reference range number line (bottom portion) in participatory design sessions as separate graphical formats. We combined them into a single infographic at the suggestion of design session participants. Reprinted from "A systematic method for exploring data attributes in preparation for designing tailored infographics of patient reported outcomes" by A. Arcia et al. eGEMs 6(1), 2. doi:10.5334/egems.190

types of graphical formats appropriate for visualization. However, those attributes can also suggest exciting design opportunities. Therefore, it is worthwhile to invest in a thorough exploration of data attributes in order to streamline the design process.

Our experience has led us to approach data exploration using three questions: (1) What does the variable mean?; (2) What values are possible?; and (3) How are values interpreted?

What Does the Variable Mean?

For many directly observed variables, such as beats per minute or cans of soda consumed per week, the meaning is readily apparent. For latent variables such as depression, however, the meaning may be more nuanced. For example, the PHQ-9, a validated instrument to screen for depression, is used both to assess the severity of symptoms and to determine if criteria for diagnosis are met (Kroenke & Spitzer, 2002). Visualization selection depends on such subtleties of meaning, in this case symptom intensity/degree versus diagnostic threshold.

For latent variables, although some can be measured using a single item (item A, Table 10.1) more often they require a composite measure derived from multiple

Table 10.1 Item examples referenced in the text

Item stem	Response options	Comments
A. "In general, would you say your health is…?" (Bowling, 2005)	Poor, fair, good, very good, excellent	Unipolar response options; increasing health
B. "Compared with 10 years ago, how is [care recipient] at recognizing the faces of family and friends?" (Jorm & Jacomb, 1989)	Much improved, a bit improved, not much change, a bit worse, much worse	Bipolar response options with neutral midpoint; change in signs of dementia
C. "I can make time for physical activity." (Donahue, Sloane, Callahan, & Mielenz, 2004)	Strongly agree, agree, disagree, strongly disagree	Bipolar response options with no midpoint; supports to physical activity
D. Systolic blood pressure	mmHg in whole numbers	General population cutpoints at 120 and 140 mmHg (American Heart Association, 2016)

Reprinted from "A systematic method for exploring data attributes in preparation for designing tailored infographics of patient reported outcomes" by A. Arcia et al. eGEMs 6(1), 2. doi:10.5334/egems.190

items. In either case, it is advisable to start by identifying the underlying construct. The following questions can help to guide searches in Google and clip art databases for reference images associated with the desired meaning.

- *Do the authors identify a theoretical framework that guided instrument development? Do they provide a clear definition of the underlying construct?*
- *What is the meaning of the items? How are respondents and/or viewers of the visualization likely to interpret them?* For example, some groups may have a culturally based understanding of a "serving" of vegetables.
- *What type of response is sought?* Common response types include frequency, intensity, duration, and level of agreement.

What Values Are Possible?

Our next step toward understanding the data was to identify the values and ranges that are possible for a given variable. Different considerations come into play for categorical/ordinal and continuous variables.

Categorical/Ordinal Variables

Variables that are categorical or ordinal typically have relatively few possible values and are easier to plan for and visualize. To understand these variables consider:

- *What are the response options and how are they encoded?* Responses to item A in Table 10.1 might be coded as poor = 0, fair = 1, good = 2, etc. The coding

scheme is important to know when information is reported as a mean and standard deviation versus a distribution. If some response options are rarely used, it may be possible to omit them in a visualization.

- *Are responses unipolar or bipolar?* Unipolar response options (item A) suggest increasing quantities (e.g., "health"). Bipolar options (item B) can be positive and negative values on a number line centered over zero.
- *Do bipolar response options include a neutral midpoint?* Bipolar response options imply a midpoint, but that midpoint is not always made available to respondents as in item C.
- *What transformations, such as collapsing categories, are possible and/or desirable?* In the case of item B, the five options could conceivably be collapsed to three: improvement, no change, and worsening. For item C, responses could be dichotomized into agreement and disagreement.

Continuous Variables

Considerations useful for understanding continuous variables include:

- *What is the scaling or metric?* Celsius, *z*-scores, grams, minutes of physical activity, and servings of vegetables are examples of metrics for continuous variables. Latent variables measured by a set of items usually result in a summed or averaged score treated as continuous even when individual items are categorical or ordinal.
- *If zero is a possible value, what is its meaning?* For ratio measures such as meters, beats per minute, and servings of vegetables, zero signifies the absence of the phenomenon. Zero for a *z*-score is benchmarked to the population mean.
- *What are the minimum and maximum possible values? What are the minimum and maximum observed values?* These values are useful not only for the design phase, but also for verifying that automated visualizations are generated correctly.
- *What is the range of typical values? Are values clustered tightly around the mean or is there a broad range of outliers?* The effect of outlier values on a visualization can be undesirable (see Fig. 10.2a). Some outliers may be omitted depending on the purpose of the visualization. If not, creative solutions must be found.
- *How much rounding is optimal?* Rounding should be a function of the nature of the variable and the purpose of the visualization. Data collected as whole numbers may be presented in smaller units to aid comparison. For example, WICER data for fruit and vegetable servings were reported in tenths (Maria, 2.0 servings; other women Maria's age, 1.8 servings). If data are presented in graphs, axis labels should be rounded to increments larger than the individual data points, as in Fig. 10.2a, b.
- *Is binning appropriate?* Conversion of continuous values into categories (binning) may be appropriate if precise values are not essential (e.g., age groups, income brackets, body mass index (BMI), or screening results).

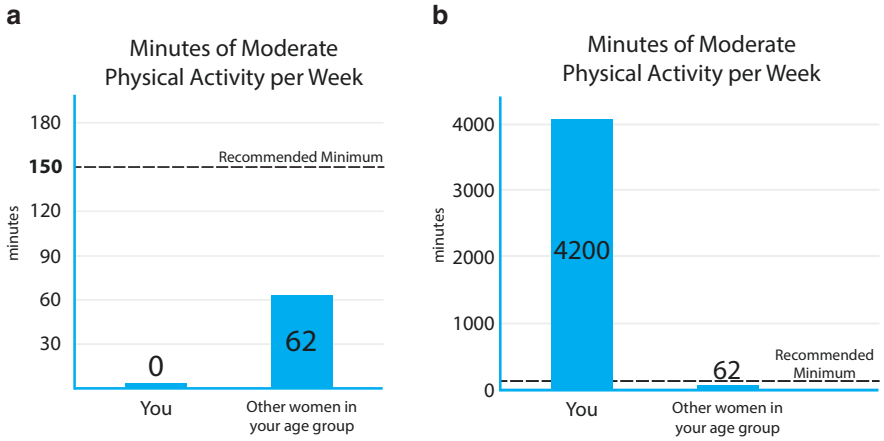

Fig. 10.2 (**a**, **b**) Infographics from WICER demonstrating design techniques to accommodate the effects of extreme values. In (**a**), a very shallow bar is used to indicate where the bar would be if the value were not zero. The remaining visual elements are proportioned as the designer intended. In (**b**), the need to accommodate a very high value obscures the recommended minimum value . Reprinted from "A systematic method for exploring data attributes in preparation for designing tailored infographics of patient reported outcomes" by A. Arcia et al. eGEMs 6(1), 2. doi:10.5334/egems.190

How Are Values Interpreted?

Having determined the meaning of a variable and the range of possible values for it, the next task is to understand the meaning of the possible values. Considerations for value interpretation include:

- *If the variable is latent, what direction is the scoring?* In other words, do high or low scores indicate high levels of the latent trait?
- *Are there value judgments associated with the values?* What values are considered "good" or desirable? Relative value can be encoded with visual cues such as color (e.g., green = healthy, red = unhealthy), visual prominence, or symbols (e.g., check marks, happy/sad faces).
- *Are there cutpoints associated with a variable?* Are there values that separate scores into meaningful categories? Cutpoints may be set by clinical practice guidelines, by instrument developers, based off of national/international norms, or even by arbitrary convention (e.g., 120 mmHg is the cutpoint between normal systolic blood pressure and pre-hypertension). If more than one set of cutpoints exist, determine which are the most relevant for the purpose.
- *Are normed scores available for the variable?* Scores compared to population norms support interpretation of values, especially when cutpoints are not in use.

Answers from the above questions will produce a quick-reference summary of the data attributes (see Harris, 2000). The designer can then use existing tools and guides exist (see Selected Visualization Resources sidebar) to support selection of an appropriate graphical format to represent the data.

Selected Visualization Resources

Visualizing health http://www.vizhealth.org/ Evidence based risk-communication visualizations
Icon array generator http://www.iconarray.com/ Icon arrays display part-to-whole relationships for communicating health risks
Chart chooser http://labs.juiceanalytics.com/chartchooser/index.html Use filters to find the right visualization for the data and download as Excel or PowerPoint templates
Choosing a good chart http://extremepresentation.typepad.com/blog/2006/09/choosing_a_good.html Decision tree for chart selection
Graphic cheat sheet http://billiondollargraphics.com/graphic-cheat-sheet/ Interactive chart selection tool
Properties and best uses of visual encodings http://complexdiagrams.com/properties Suggested encoding elements according to data characteristics
See http://selection.datavisualization.ch/ and http://dataviz.tools/ for an extensive curated selection of data visualization tools

Case Study 1

Getting to know the data was an important early step for three main reasons. One, the data characteristics imposed limitations on possible designs. For example, to display a response to the question "During the past 30 days, for about how many days have you felt sad, blue, or depressed" (Centers for Disease Control and Prevention, 2000) we could show the total number of days but not their relationship to each other (i.e., all in a row vs. scattered throughout the month). Furthermore, research shows that when designers begin designing prior to fully understanding the data their assumptions about the patterns likely to be found in the data are often inaccurate (Bigelow, Drucker, Fisher, & Meyer, 2014).

Two, the precise variable meaning and the data characteristics sometimes suggest design opportunities or new ideas. Three, understanding the full range of values allows inclusion of all relevant use cases and paves the way for visualization automation. For WICER the biggest design and automation challenges arose from inconvenient outlier and non-missing zero values. Figures 10.1 and 10.2a, b illustrate how some of the considerations outlined above influenced design decisions.

(continued)

Based on feedback from the WICER participants who generated the data, we selected bar graphs as the most effective presentation for physical activity (see Fig. 10.2a, b) (Arcia et al., 2016). An accurate title was sufficient to communicate the meaning of the variable. The recommended minimum, shown as a dotted line hovering above both bars, communicated the goal to be reached. The zero and outlier values presented a challenge. For zero, complete absence of a bar would potentially confuse, even if labeled. Our solution was to suggest zero with a shallow bar (Fig. 10.2a). The large outlier value in Fig. 10.2b distorts the relative proportions of the elements and the recommended minimum is no longer shown on the *y*-axis. Although aesthetically suboptimal, we kept this design because the proportion of high outliers was very small, and the purpose (i.e., gist comprehension) was not compromised.

Different considerations came into play for BMI (see Fig. 10.2). The metric, kg/m^2, is not intuitive for the general public, meaning the infographic had to support identification of the value and interpretation of the metric. Based on our research of visualizations in this area and on participant feedback we elected to combine body silhouettes that evoke the meaning of the BMI categories with a number line to demarcate the reference ranges. The BMI infographic had to support verbatim comprehension over gist comprehension, because one of the cutpoints is between whole values (18.5) and because personal change along the continuum can occur in small increments (tenths). The cutpoints are not equidistant, which is a drawback aesthetically, but we determined that equality of intervals along the number line was preferable to over making the BMI categories visually symmetrical.

To select the range of values to display we considered (a) values that would allow visually balanced gradation in body silhouettes, (b) placement of the most common values in the center of the image, and (c) adequate spacing between values for ease of reading. However, a substantial proportion of respondents have values above the 15–35 range. In those cases the indicator box sits off the number line but overlaps the end of the arrow to suggest its placement, if number line was extended. We used green, orange, and red to encode value judgments associated with the categories.

Iterative Design

The next step in our visualization method is iterative design using a hybrid participatory design process. Unlike a design process that is entirely participatory, a hybrid process begins with initial prototyping by experts prior to moving on to participatory design sessions. Iterative design begins with initial prototypes created by experts and concludes with finalized information visualization designs informed by

members of the intended audience. The rationale for a hybrid approach is that it is generally easier for the typical design session participant to choose from among and suggest changes to several options than to invent something from scratch. An important goal in the iterative design process is to identify the visual and symbolic language that is shared by the members of the health communication/design team and the intended audience.

Initial Prototyping

For WICER, a large, multi-disciplinary team of clinicians and scientists, some of whom had arts backgrounds, collaborated on the initial prototyping. A graphic designer was engaged at the end of the process, after the participatory design sessions had concluded. Armed with experience, we were able to streamline the process substantially for NHiRP and carry out initial prototyping with just one nurse scientist and a graphic designer. Depending upon the goals of the project, it may be useful to include an illustrator or animator at this stage.

For initial prototyping, we created many sketches to display each variable so as to have options from which to choose (see Arcia et al., 2013 for more details). The idea is to explore the range of graphical formats possible for a particular variable (both standard and novel) as well as variations within a particular format. The insights gained into the attributes of the data become useful at this point. What kinds of images convey the desired meaning? What visual and symbolic analogies can be incorporated? How can important features such as cutpoints or "good" values be highlighted? Visualization expert Edward Tufte encourages his workshop participants to consider, "What works in the wild?" That is, what formats, images, symbols, interfaces, etc., are familiar and successfully being used by the intended audience?

The application of basic information design principles (Katz, 2012; Lipton, 2011; Munzner, 2014) and lessons learned from prior visualization research (Ancker, Senathirajah, Kukafka, & Starren, 2006; Houts et al., 2006) can be used to narrow down and iterate upon the strongest sketches. Hallway testing, in which feedback is solicited from naïve viewers (such as by buttonholing someone in a hallway), is a very useful technique for getting a fresh perspective between iterations. The best ideas can then be fully fleshed out to yield the initial prototypes to be presented in participatory design sessions.

Participatory Design Sessions

A good participatory design session will include four to eight people recruited from the intended audience and last 1½–2 h (see Arcia et al., 2016 for additional methodological detail). If many opinions and lively discussion are desired, as many as 12

may be accommodated but for sensitive or emotionally charged topics, smaller groups are more desirable as they allow time for individuals to share their stories.

For both WICER and NHiRP, we gave participants identical stacks of 8½″ × 11″ card stock printed with a single infographic design per page. Infographics were tailored for fictional people with simulated data. Looking at the designs one by one, we guided discussion by asking, "What information do you think we are trying to convey with this image? What does it mean to you?" After considering a group of designs relating to the same variable, we asked the group to indicate by voice or hand vote which of the images they preferred and why and then solicited suggestions for improvement. Any additional questions will depend upon the topic and purpose of the visualization. For example, for infographics related to physical activity, nutrition, BMI, or blood pressure, we asked if the image would motivate them to address the health issue. For caregivers viewing information about mental health or caregiving burden, we asked a more open-ended question about how they would react to seeing a particular design.

A short peer-debriefing session between staff members immediately following the design session can be used to discuss impressions and make design decisions about how to iterate. Designs not favored by participants can be dropped, and successful ones can be further refined based on feedback. Occasionally, ideas for an entirely new design will emerge from design sessions. Scheduling design sessions about a week apart allows time to iterate accordingly.

It is not always obvious which participant feedback to pursue and which to set aside. Sometimes the solution is to gather more data and present the same options to additional groups. Additional data can help clarify the difference between a representative viewpoint that should be accommodated and an idiosyncratic, personal viewpoint that does not represent the larger group well. As the sessions progress, the differences between designs narrow and a consensus emerges as to which designs meets the stated purpose for the large majority of participants. This is the point of design saturation and the end of the participatory design process.

Case Study 2

The importance of engaging members of the target audience in the participatory design process cannot be understated. Some of the ideas that we developed during initial prototyping for WICER were confusing to or misinterpreted by participants whereas others proved to be more successful than we would have anticipated (Arcia et al., 2016). For example, a number of prototypes that we explored employed repeated icons to represent multiple instances of a more general class of things, such as apple icons to represent servings of fruit or silhouetted runners to represent days with physical activity. Many participants interpreted the icons very literally and did not spontaneously generalize to include other types of fruits or to activities beyond running.

By contrast, icons used as symbolic analogies, such as the use of a battery to represent sleep and energy or stars to rate overall health, were nearly universally understood. We speculate that this finding can be explained by participants' level of familiarity with specific graphical conventions. Purveyors of movies and other products have trained us in the use of a five-star rating system and anyone who uses a portable device understands the consequences of a depleted battery icon. As Edward Tufte would say, these conventions have proven success "out in the wild." It appears that some of the other iconographic formats we explored were not familiar to our target audience and therefore were frequently misinterpreted. Given the culturally specific nature of exposure to graphical formats our findings will not be applicable to all audiences, hence the importance of participatory design with each target audience.

Automation

This step in the method applies to visualizations that vary because they are tailored in some fashion. A style guide is useful for codifying the design specifications and communicating them to the programmer. Once programmed, the visualizations must go through quality control testing to ensure they render as planned.

Codifying Design Specifications

A style guide is a structured communication tool in which the design specifications of each visualization are codified in stand-alone entries (see Arcia, Velez, & Bakken, 2015 for details). The advantage of using a style guide is that it serves as a reference for how the finished product should look and behave but does not impose a specific programming approach.

For the WICER Style Guide (see Fig. 10.3) the fields we filled for each entry specified the variables (and any transformations thereto) needed to build the infographic, the comparison groups to be used (if any), the units of measure (and rules for rounding), a description of how tailoring affects the image, any reference ranges or criteria (e.g., blood pressure categories), Spanish translations of all text, and the versions to be produced (e.g., English and Spanish, male and female). We included a notes field with miscellaneous instructions for how to treat extreme and non-missing zero values. Each entry is illustrated with one or more sample images. In order to prepare for the formal comprehension testing that we used to evaluate the WICER infographics, we also included fields for text-only versions of the information shown in infographics as well as instructions for tailoring the text. We used the same

Body Mass Index (BMI)

Variable(s):	Sex, BMI (bmi_kgm2), BMI Category (create a new variable based on below criteria)
Units:	Tenths
Tailoring:	Indicator box has value inside and is centered over value location on number line. Value also shown on belly of corresponding figure.
Criteria:	<18.5 is underweight; 18.5-24.9 normal; 25-29.9 overweight; >30.0 obese
Notes:	Indicator box sits just past the arrow for values <15 or >35 as shown below
Versions:	English, Female English, Male Spanish, Female Spanish, Male

Fig. 10.3 The above excerpt from the WICER Style Guide includes the fields necessary to produce the BMI infographic shown in Fig. 10.1

font and color palette across infographics and so these were specified at the beginning of the style guide. For NHiRP, we have added a field to specify the values to be used during quality control testing.

When considering how an image may be affected by tailoring, it is desirable to have as few "moving parts" as possible because this simplifies the subsequent automation programming. For example, in our BMI infographic (Fig. 10.1), we used four static backdrops (varying by gender and language) and the only elements that change with tailoring are the location of the marker along the number line and the value shown inside of it and the body silhouette.

Programming and Quality Control Testing

In order to tailor the WICER infographics automatically, we developed a novel, adaptable, reusable, and generalizable software approach called EnTICE^3 (*E*lectro*n*ic *T*ailored *I*nfographics for *C*ommunity *E*ngagement, *E*ducation, and *E*mpowerment).

Infographics are programmed individually into EnTICE^3 as a set of rules that govern the selection and relative placement of metadata and graphical components based on the specifications laid out in the style guide. Using R Studio as an interface, the user directs EnTICE^3 to the desired dataset and ID number(s) for which individual and population data are to be drawn. EnTICE^3 then uses its rule-based programming to assemble infographics from the graphical components in its repository (see Fig. 10.4). The finished infographic is saved as a pdf file. Depending upon the graphical format chosen, it may not be necessary to write code from scratch. There are online libraries of visualizations from which R and D3.js code is freely available (see Selected Visualization Resources sidebar).

Quality control testing requires very careful attention to detail to verify that the infographics appear as they should regardless of the data entered. For variables with only a handful of possible values, testing is straightforward. Problems are most likely to arise with continuous variables, especially for decimals, extreme values,

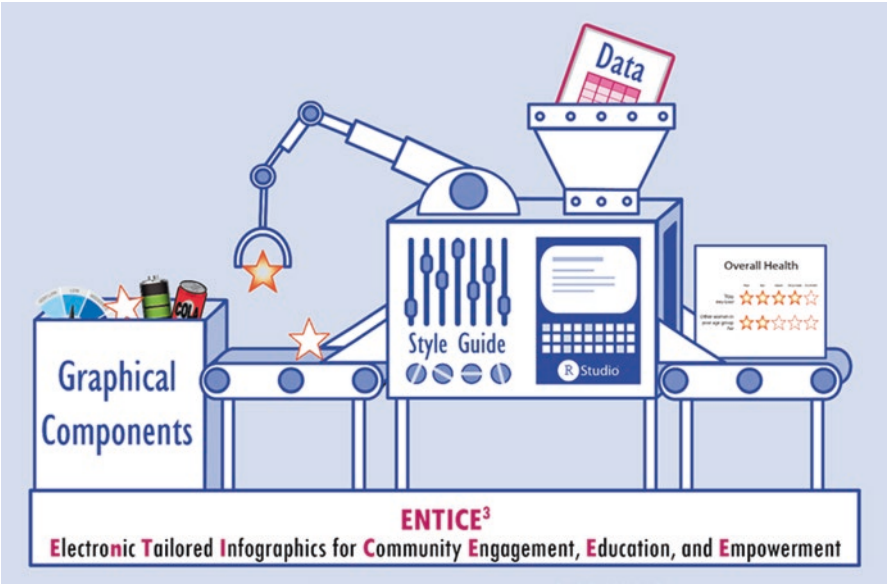

Fig. 10.4 EnTICE[3] uses the data provided by the user to assemble infographics from the graphical components in its repository according to style guide specifications. R Studio is used as the interface for running EnTICE[3]

and non-missing zero values (see Fig. 10.2a, b). One motivation for gaining a thorough understanding of the data attributes is precisely to anticipate and avoid difficulties with automation. Binning values and rounding to larger (e.g., 10s, 100s) numbers can simplify the process by limiting the possible outputs to be rendered. Illegal and out-of-range values should also be tested to ensure that the system can detect them and return an appropriate error message.

Evaluation

The purpose of evaluation is to determine the extent to which a visualization achieves the desired outcomes. As such, the method of evaluation should be selected for its sensitivity to those outcomes. Because comprehension support was the primary purpose for the WICER infographics, we conducted formal comprehension testing.

Suppose the purpose of a visualization is to prompt behavior change. An exploration of viewers' intent to change behavior would be a good first step but ultimately, evaluation would need to compare the behaviors of people exposed to the visualization in comparison to those not so exposed. It is beyond the scope of this chapter to cover the myriad forms that evaluation can take. Rather, we will focus on two types of evaluation, heuristic evaluation and comprehension testing, as illustrative case studies.

Heuristic Evaluation

Heuristic evaluation is a usability inspection method in which experts compare the design being evaluated against a set of heuristics. The heuristics may vary depending upon the object being evaluated. For example, Nielsen's general user interface heuristics have been broadly implemented to a variety of digital artifacts and are considered a discount usability method because a relatively small number of experts can detect the majority of usability problems (Nielsen, 1995). Others have proposed heuristics for specific types of applications or populations such as mobile apps for older adults or for information visualization evaluation (Silva, Holden, & Jordan, 2015; Zuk, Schlesier, Neumann, Hancock, & Carpendale, 2006).

Heuristic evaluation complements testing with intended users of an artifact since it tends to focus on ease of use while the latter has a major focus on usefulness (Yen & Bakken, 2009). Approaches to conducting the heuristic evaluation vary in level of formality and structure. We have used a number of approaches in our research. In some instances, the experts have been asked to think aloud as they explored a system and their interactions and utterances have been captured with specialized usability software (Choi & Bakken, 2010). In other situations, we have applied an approach in which, using a heuristic checklist, each expert provides general comments about each heuristic and then provides a rating on the severity of the heuristic violation from cosmetic problem only to usability catastrophe (Allen, Currie, Bakken, Patel, & Cimino, 2006; Bright, Bakken, & Johnson, 2006).

For both WICER and NHiRP, we have used a group, rather than individual, approach to heuristic evaluation, in which experts well-versed in heuristics assess information visualizations and make recommendations for improvement (Arcia et al., 2013). Recently, we have formalized the group and its processes as the Columbia Visualization Design Studio.

Comprehension Testing

We initially elected to conduct a randomized controlled trial to formally compare infographics to text alone with respect to comprehension and perceived ease of comprehension. As a secondary consideration, we also asked participants to rate how motivated they were to address the health issue presented in some of the infographics. In our experimental design, participants were randomized to four groups: A1, A2, B1, and B2. Group A served as group B's control, and vice versa; group 1 saw text first, group 2 saw infographics first.

For example, group A was presented with text-only about prolonged stress and an infographic on depression symptoms while group B was presented an infographic on prolonged stress and with text-only about depression symptoms (see example in Fig. 10.5). This design was used to minimize potential sources of bias. Decks of infographic and text-only slides were tailored for participants with their own survey data. For each slide, participants completed a comprehension question

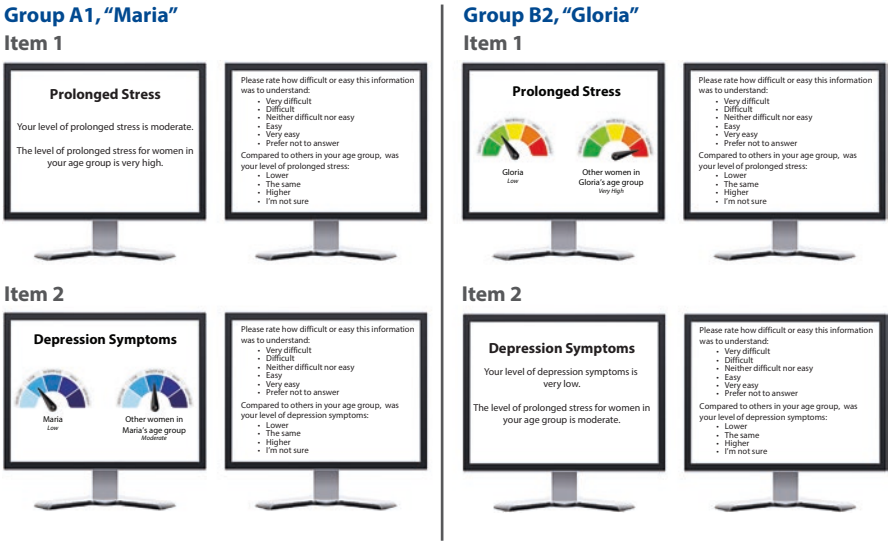

Fig. 10.5 Visually and conceptually similar infographics serve as controls for each other. "Maria" sees text about prolonged stress and an infographic for depression symptoms while "Gloria" sees an infographic for prolonged stress and text about depression symptoms

(e.g., "Is your BMI category underweight, normal, overweight, or obese?") and a rating of the ease of comprehension of the item ("Very difficult" to "Very easy" to understand).

We did not expect that the infographics would perform equally well with respect to one another; some designs are likely stronger than others. Therefore, the key to our experimental design was that we were able to present infographics in visually or conceptually similar pairs. This allowed us to show both infographics and text to each group so that any differences between the two formats could genuinely be attributed to the format and not to variations in the quality of the infographics.

The comprehension test was designed to be largely self-administered with infographics and multiple choice questions shown separately on side-by-side screens with a research assistant on hand to provide technical support. However, after collecting data from about half of our target sample size of 144, we elected to change our approach because we noted that despite orienting participants to the task, many answered the questions according to their feelings, memories, or opinions on the topic rather than on the information presented. The multiple choice format also appeared to be unfamiliar to and problematic for some of the older participants whose educational attainment was equivalent to no higher than middle school.

As a result, we will be moving forward with a cognitive interview-style comprehension assessment that may be more culturally appropriate for our participant population. We speculate that research teams working with populations accustomed to computer-based multiple choice testing may still meet with success using our initial approach.

Emerging Trends and Future Opportunities

Consumer Health Informatics to Support Self-Management

For both WICER and NHiRP the intent was not only to create infographics that were understandable, but also to motivate action, particularly self-management activities. Although significant literature exists regarding the efficacy of consumer-facing technology-based behavior interventions (Free et al., 2013; Tao, Wang, Wang, Liu, & Qu, 2017), the evidence related to populations with low levels of health literacy is limited. In contrast to broadband at home, cellular phones are ubiquitous among most Hispanic populations and smartphone use ownership is similar to non-Hispanic whites (Rainie, 2017). Moreover, the number of Hispanics who use their phones for health-related purposes is increasing. This creates the potential for incorporating both static and interactive infographics as a strategy for enhancing self-management behaviors. In addition, tethered personal health records, which have traditionally been web-based, are now evolving to mobile-friendly user interfaces or apps.

Integration with Care

Patient-reported outcomes and patient contextual data are anticipated to play a critical role in improving health care delivery and patient experiences with care. A patient-reported outcome (PRO) is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else (Deutsch, Smith, Gage, Kelleher, & Garfinkel, 2012). This information is gathered from patients and families via the Patient Reported Outcomes Measurement Information System (PROMIS), funded by the National Institutes of Health (Patient-Reported Outcomes Measurement Information System, 2017). PROMIS data are collected using standardized measurement questions so clinicians can use it to augment an individual's care, or so it can be summarized for population level health management. PROs include information on quality of life, symptoms, and activities of daily living. They are particularly relevant for patients with multiple chronic conditions, elders, and those with functional impairments (Barile et al., 2013).

Despite their value, PROs are not well integrated into the care process. Most electronic health records are not designed to import these data in a usable format. Additional challenges to presenting PRO data stem from the fact that they change as a patient's condition improves or worsens. Visualization can play an important role in facilitating the use of PROs. Application of sound design principles can ensure visual summaries of PRO data are designed to efficiently integrate into electronic record systems and to present information in a way that points toward appropriate action. Visual displays can also be created to return PRO results to patients to support their engagement with their care. The processes described here can guide develop-

ment of visual displays that reduce the cognitive processing effort required by patients and providers to use PRO data for shared decision-making. Visualizations that appropriately return PRO results also can support patients to manage their own care and attain care goals.

Other Data Streams

Data for producing health visualizations may come from many sources. Patients now collect high frequency, longitudinal health data outside of the clinical setting, using mobile technologies. Nearly 90% of Americans have smartphones and about 21% use smartphone applications, wearable devices, and remote monitoring devices to track health (Poushter, 2016). Patient-generated health data is increasingly being sent to healthcare providers for review.

Rules for the new payment models being implemented, as part of national efforts to control cost and improve care, stipulate that patients have the opportunity to view, download, and transmit their health data to providers (Centers for Medicare and Medicaid Services (CMS), 2016). These systems themselves produce data that will provide opportunities for development of visualizations that communicate meaning to consumers about quality in the organizations that provide healthcare. One example is the Merit-based Incentive Payment System (MIPS) currently being implemented by the US Health and Human Services Administration (Medicare Access, 2015).

Conclusions

Patient engagement in self-management requires educating patients, families, and caregivers about their health conditions and empowering them to become involved. A key means to this end is through the return of personalized data and information about their care. When evidence-based visualizations, based on sound design practices, facilitate and augment these efforts, a compelling entry point emerges for patients at all levels of health literacy to engage in the health care process to achieve the best possible outcomes.

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Chapter 11
Telemedicine and Pediatric Urgent Care: A Vision into the Future

Mordechai D. Raskas, Kari Gali, Dana Aronson Schinasi, and Shayan Vyas

Telemedicine was once a service for only the most remote care delivery, to areas without other feasible means to have satisfactory care. With evolution in technologies and connectivity, paired with social drivers for convenience and value-based care, telemedicine is now a budding industry with products and services that will likely touch every medical specialty over the next decade. As many as 84% of healthcare executives describe telemedicine as critical to the future success of their organizations (Foley & Lardner LLP, 2014). In 2015, an estimated 1.25 million direct-to-consumer (DTC) telemedicine visits occurred in the United States (US) (American Telemedicine Association, 2015), and this number is expected to grow exponentially in the coming years. The global telemedicine market is expected to be

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M. D. Raskas (✉)
Division of Telemedicine and Clinical Informatics, PM Pediatrics, Greenbelt, MD, USA
e-mail: mraskas@pmpediatrics.com

K. Gali
Express Care Online, Distance Health Cleveland Clinic, Cleveland, OH, USA

Patient Safety Leadership Program, University of Illinois Chicago, Chicago, IL, USA

D. A. Schinasi
Division of Emergency Medicine, Emergency Care Connect, Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University Feinberg School of Medicine, Evanston, IL, USA

S. Vyas
Critical Care Medicine, Nemours Children's Hospital, University of Central Florida, College of Medicine, Orlando, FL, USA

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more than 34 billion dollars by the end of 2020 (Monegain & Healthcare, 2015). The majority of US healthcare systems are exploring remote health technologies to expand their care networks and provide care to a wider variety of patient populations (American Hospital Association, 2015; American Telemedicine Association, 2016).

Telemedicine refers to the use of medical information exchanged from one site to another via electronic communications to improve a patient's clinical health status. Telemedicine includes a growing variety of applications and services using two-way video, email, smartphones, wireless tools, and other forms of telecommunications technology (American Telemedicine Association, 2016). The term telehealth often encompasses a broader definition of remote healthcare that does not always involve clinical services.

Although telemedicine has existed for decades, the market is now exploding because of advances in technology, medical provider shortages (particularly in rural areas), a shift to population health management, and attempts to decrease health spending. Another significant factor influencing adoption of telemedicine is the voice of the consumer. An emphasis on convenient, prompt quality services has driven market demand. A 2014 survey identified almost 75% of US patients being open to the telemedicine format and an 86% patient satisfaction rate among previous users of telemedicine (NTT Data White Paper, 2014). Telemedicine services are offered synchronously (through live, interactive videoconferencing), asynchronously (using a store and forward capacity), or through remote monitoring and occur in acute care, inpatient, and outpatient settings. Early adopter specialty areas, such as teleradiology, have paved the road for achieving successful implementation of quick, around-the-clock, access to specialty consultation, regardless of geographical location. Telepsychiatry and teledermatology have additionally addressed the challenges of medical provider shortages and misdistribution of providers in these fields.

While telemedicine is ready to explode, it is not clear who will be driving the delivery. Urgent care, which succeeded by appealing to consumer demand and convenience, may be the most at risk of being disrupted by telemedicine. Alternatively, urgent care, with brick-and-mortar networks, may also be the best positioned to steer this innovation.

In this article, we provide an evidence-based review of the current and potential role of telemedicine in pediatric urgent care. We review advantages that telemedicine adds, discuss use cases, and explore challenges encountered in adoption of urgent care telemedicine in pediatrics. This article concludes with a summary of resources available for providers considering or already implementing an urgent care telemedicine program for pediatric patients.

Effectiveness of Telemedicine for Pediatric Acute Care

Telemedicine has shown to be safe and effective for evaluation of uncomplicated conditions in the urgent care setting (Courneya, Palattao, & Gallagher, 2013; Mehrotra, 2013). Much has been written about the potential for telemedicine to increase access

to care, but the majority of published work to date has been in adult medicine (Hickson, Talbert, Thornbury, Perin, & Goodin, 2015; Mehrotra, Paone, Martich, Albert, & Shevchik, 2013a, 2013b). In 2015, the American Academy of Pediatrics (AAP) published a statement cautioning that telemedicine used for episodic care by nonmedical home providers has the potential to disrupt continuity of care, and create redundancy and imprudent use of health care resources, "Although such novelty care appeals to parents because it can be faster, more convenient, and more affordable than an office visit, the loss of continuity of care, quality of care, and patient safety shows why this telemedicine care model should not be embraced." (Marcin, Rimsza, & Moskowitz, 2015). An updated AAP statement is anticipated in 2017.

Despite some hesitance, there is a growing body of evidence regarding the effectiveness of video and audio-based interventions for a variety of acute conditions seen in pediatric care (Mehrotra, 2013). In an evaluation of tele-visits for sinusitis and urinary tract infection, physicians were less likely to order testing during the tele-visit and more likely to prescribe antibiotics; yet there was no difference in how many patients required a follow-up visit, as proxy for misdiagnosis or mismanagement (Mehrotra et al., 2013b). In a study using telemedicine for the diagnosis of common pediatric acute illnesses, the reproducibility of telemedicine diagnosis did not differ from that of in-person diagnosis (McConnochie, Conners, Brayer, et al., 2006). Another study, involving pediatric rashes in a simulated direct-to-consumer model, demonstrated a high concordance of diagnoses and treatment plans, when comparing in-person and telemedicine visits (Raskas, Badolato, & Mathison, 2016). Not only have published clinical outcomes shown to be similar to in-person encounters, but there are consistent reports of high patient satisfaction related to increased convenience as well as reduced costs of care (Alverson, Holtz, D'Iorio, Simmons, & Poropatich, 2008; Spooner et al., 2004).

Telemedicine Opportunity in Urgent Care

Telemedicine offers many advantages for patients, providers, and public health. For patients, telemedicine offers convenience and enhanced access to care. For providers, telemedicine can provide improved efficiency and access to specialty care. For public and population health, telemedicine may increase access to care and reduce spending.

Improving Convenience of Care with Direct-to-Consumer Telemedicine

Convenience is the key driver for consumer interest in telemedicine. In a DTC telemedicine model, patients can initiate a medical visit without leaving the comfort of their own home. Numerous companies and health organizations now offer DTC

telemedicine in which patients can connect via secure video with a provider, often immediately, and obtain a video consultation with a physician. In most states, physicians can prescribe medications (excluding controlled substances). Visits typically last 10–20 min and cost $40– $50 (Yamamoto, 2014). Some payers are now reimbursing or directly covering such services.

In urgent care, this may be particularly appealing as many visits are driven by convenience alone. Unpublished data from Nemours' telemedicine platform for pediatric urgent care, Nemours CareConnect, has shown parent satisfaction scores as high as 94–96% during the program's first 10 months of DTC pediatric urgent care (Vyas, 2016). Convenience of care in the home has become a reality due to the proliferation of technology such as smart phones, video chat, and high speed internet. According to the Pew Research Center, 91–94% of all Americans own a cell phone (Pew Research Center Website, n.d.) which is an opportunity for access to care. DTC care is available beyond standard working hours, in some cases even 24/7. The reduction in travel time combined with the increased available hours of telemedicine, allow parents to avoid or reduce days off of work. Staying in the home environment also decreases the risk of transmission of infectious illnesses to and from the patient. This applies both to routine illnesses such as upper respiratory infections and evaluating patients for more concerning diseases, such as Ebola.

For providers, DTC telemedicine allows opportunity to see a patient in a home environment, which can provide clues or information from this location that would otherwise be absent during an in-office visit. Consider a previously unrecognized case of neglect or abuse in which the provider might obtain important history elements simply by observing the home situation. Or similarly, what better way to educate a new parent about newborn care, back-to-sleep, child-proofing, and infant feeding than seeing the current home environment.

Improving Care Efficiency

For urgent care centers (UCCs), telemedicine can allow for load balancing. That is, when patient load is particularly high at one location, patients are provided an option to see a remote provider with a shorter wait time (Premarathne, Han, Khalil, & Tari, 2013). Load balancing may be an important feature since customer service and convenience are such an important part of the success of urgent care. For large networks, utilizing physicians at other locations is an appealing prospect to decrease wait times during periods of surge. In 2015, CVS piloted an in-store telemedicine service as a test environment for future load balancing. A survey of 1700 customers found that 95% were "highly satisfied" with the encounter and 35% actually preferred a telemedicine visit over an in-person visit with a doctor (Healthcare Dive, 2015).

Providing Subspecialty Access to Expand Services

Pediatric UCCs can develop telemedicine programs with specialists to expand their services and provide added convenience for their customers. One of the most well-researched and clinically effective versions of provider-to-provider telemedicine is telestroke (Akbik et al., 2017), in which neurologists are used to consult on patients located in emergency departments (EDs) who present with neurological deficits concerning for a stroke. The remote neurologist performs an exam via telemedicine and helps the emergency physician manage the patient. There are a variety of successful specialty telemedicine consultation models, although a select few practically apply to urgent care.

Using Pediatric Expertise to Increase Reach

Pediatric UCCs can use their distinct pediatric expertise to be the consultants to select populations such as general UCCs, general EDs, public health clinics, or schools. Some health centers may have very limited pediatric knowledge and may want to contract with a pediatric UCC to improve the services to their customers. This could be similar to models in which pediatric intensivists provide telemedicine expertise to community EDs caring for critically ill children (Yang et al., 2015). A robust pediatric UCC telemedicine program could allow consultations at a variety of events and locations using only a limited number of health professionals, such as consultations to athletic tournaments staffed only with trainers, regional events staffed only with paramedics, or school systems staffed only with nurses (or no medical personnel).

Improving Public Health and Access to Care

As a public health initiative, telemedicine may decrease expensive ED utilization, non-urgent emergency medical services activation, and relatively more expensive urgent care, retail care, or primary care visits. If DTC telemedicine can be cost effective, there is potential for reductions in health care spending. From unpublished data, Nemours Children's Health Care System's 24/7 DTC telemedicine platform for pediatric urgent care demonstrated on post-visit surveys that 60% of parents would have gone to an ED, urgent care center, or retail health clinic if the service was not available (Vyas, 2016). The counter-argument for cost savings is that reducing barriers to access may actually increase total visits which may not reduce health spending. However, improving access to care with telemedicine may be particularly advantageous for populations without convenient transportation and for populations who have limited access because of other child care needs.

Improving access with telemedicine allows for care earlier in the cycle of an illness which may prevent sequelae of a preventable illness progression such as a complicated pneumonia.

Reducing ED utilization and hospital admission is an important driver for the success of telemedicine as it relates to value-based care. Pediatric estimates of total avoidable ED use range as high as 56% of all visits (Weinick, Billings, & Thorpe, 2003), and a recent analysis found that nearly 28% of all visits to a pediatric ED could have been handled with telemedicine (University of Rochester News, 2008). According to the National Center for Health Statistics, the average ED visit costs $1049 (Agency for Healthcare Research and Quality, 2012), while the average expense for a primary care office visit is $145 (Davis & Carper, 2012). Pediatric urgent care telemedicine visits cost $40–50 (Yamamoto, 2014) and this figure does not include the additional savings from reduced waiting, reduced travel time, and other related factors.

If UCCs can develop subspecialty telemedicine consultations, this may decrease the need for hospital transfer and costs for ED specialty care that could be deferred to outpatient follow-up. The Electronic Children's Hospital of the Pacific, an internet-based pediatric subspecialty consultation service provided for US-associated Pacific Islands, demonstrated that transport was avoided in 12% of cases (Callahan, Malone, Estroff, & Person, 2005). Similarly, using telemedicine for patient transport can streamline care and promote direct admission, bypassing the extra expense of ED care. In a pilot using telemedicine for pediatric inter-facility transport, 80% of medical control officers felt they had a better understanding of patient condition and 70% felt that video assisted with disposition decisions (Patel, Hertzog, Penfil, & Slamon, 2015).

Specific Use Cases for Telemedicine in Pediatric Urgent Care

Telemedicine can and should be provided by pediatric urgent care providers. UCCs are well suited to provide telemedicine due to their ability to triage emergencies and treat a wide range of illnesses and acuity levels in a relatively efficient manner. This section outlines a practical and strategic plan for how UCCs can augment their practices with telemedicine using a variety of clinical models, including: load balancing, "hub and spoke," "satellite," school-based care, DTC, subspecialist consults, and mentoring.

Use of Kiosks for Load Balancing

UCCs pride themselves on a short door-to-door time, and load balancing via telemedicine can further reduce this time. One version of this model involves putting enclosed kiosks at busier sites to allow remote providers to see patients. These

enclosed kiosks can be fully operated by the patient or can also include an on-site telemedicine assistant who helps the patient use the equipment. Alternatively, a mobile telemedicine cart can be used in any private room within the facility. Load balancing kiosks may also be an effective strategy for an urgent care location that has outgrown its physical space, as kiosks may be more space economical and versatile in their placement.

Implementation of "Hub and Spoke" Specialty Care

Pediatric UCCs could serve as the remote provider, adding expertise for the acute care of pediatric patients located at non-pediatric sites, often referred to as a "hub and spoke" model. Pediatric UCCs should consider offering these services to schools, general UCCs, and large local facilities where available pediatric care is limited (e.g., amusement parks, professional/collegiate sporting events, etc.).

School clinics may be optimal remote sites to communicate with pediatric UCCs. The schools and parents typically opt into an agreed upon relationship with a set of remote providers and when appropriate set up a consultation with the remote pediatric provider (McConnochie, Wood, Herendeen, et al., 2010). Many of these programs initiated with grant funding have been transitioned to traditional billing mechanisms. Patients will often be in a school nurse's office and a telemedicine cart is used to connect the patient and nurse with the provider, and at times, with the parent as well. By having UCCs provide this service via telemedicine, the patients are afforded the opportunity to seamlessly obtain further testing or in-person care at the UCC, if clinically needed.

Development of Satellite Relationships

Similar to a "hub and spoke" model, a satellite model uses telemedicine kiosks to communicate directly with a health system. Brand-friendly health companies have deployed these at convenient locations, for example, supermarkets (Sioux Falls Business Journal, 2015). In another example, Cleveland Clinic now offers kiosk services at participating CVS Pharmacy locations in Ohio (Samsung Business Insights, n.d.), allowing patients to see a provider and enter its healthcare system from a non-traditional location. This allows a patient to utilize convenient retail yet access reliable health networks. UCCs with strong local brand presence can capitalize on this model and offer remote satellite kiosks to extend care outside their typical network, while appealing to the convenience to fit the consumer's daily routine.

Initiation of Direct-to-Consumer Platforms

Pediatric UCCs may be ideal for DTC telemedicine because of brand identity, pediatric-specific service, and the ability to provide further or ongoing care when needed. Many large employers are encouraging DTC telemedicine to decrease ED visits and thereby decrease their health insurance costs; however, many DTC telemedicine organizations lack trusted pediatric expertise or mechanisms for ongoing care.

An increasing number of vendors are marketing and selling devices designed for patients to use in their own homes and improve examinations. Some devices are attachments to smart phones, while others are standalone tools. These devices are either single standalone peripherals such as stethoscopes, thermometers, or otoscopes or a combination of the above. Combining these devices with an established network of trusted local DTC care can create a far more robust DTC telemedicine offering.

For pediatric UCCs, providing DTC telemedicine may be an important driver for growth, both to add new patients and provide convenient access for existing patients. Additionally, telemedicine is likely an effective marketing tool and can promote branding and a range of services which may be appealing to potential customers.

Development of Subspecialist Consultation Offerings

Offering pediatric subspecialty consultation improves the UCCs' range of services and potentially prevents transfer to a hospital for subspecialty care. Pediatric UCCs should explore local options for telemedicine with pediatric subspecialists via secure video platforms to examine patients and provide diagnostic and therapeutic advice to the urgent care provider. Radiologists currently provide a similar service by reviewing imaging remotely and the telemedicine model of remote consultant could be expanded to include dermatology, neurology, orthopedics, ophthalmology, and other relevant pediatric specialty services. Similarly, for acutely ill and injured children who do require in-person care at an ED or a direct hospital admission, developing telemedicine relationships with local hospitals can improve transition of care via facilitation of appropriate patient transport, and directed admissions.

Offering Mentorship

Finally, there is an increasing use of telemedicine as a teaching tool for healthcare providers, particularly community providers caring for medically complex patients. Project ECHO, centered in New Mexico, has been a prominent example of this use of telemedicine (Arora et al., 2007). Indeed, the US House of Representatives and

US Senate recently passed a bill that would require the Department of Health and Human Services to study the Project ECHO model, which could ultimately lead to a significant expansion of similar models (Landi, 2016). Pediatric urgent care providers can both be recipients of knowledge through such a model (e.g., from pediatric specialists) and serve as mentors (e.g., to general urgent care providers).

Challenges and Limitations

While telemedicine offers many opportunities to provide pediatric urgent care, there are significant challenges that need to be addressed for successful implementation and sustainability. Patient safety, quality, startup and operational costs, limited reimbursement, multi-state licensure, regulatory requirements, lack of system integration and technology all pose challenges and should be key priorities for telemedicine expansion.

Quality and Safety

Patient safety and quality is critical when providing acute care services, yet there is a lack of evidence identifying and supporting the establishment of safe, effective, efficient processes and outcomes when using these technologies (Guise, Anderson, & Wiig, 2014). Variable settings for DTC telemedicine encounters pose both potential and actual risk for patients, providers, and organizations (Guise et al., 2014). A recent study of online teledermatology, using simulated patients, demonstrated that several major diagnoses were missed (Resneck et al., 2016). However, this study specifically excluded websites or apps that include live-interactive video. Nevertheless, it is likely that telemedicine, even in ideal conditions, may not provide an equivalent level of diagnostic accuracy when compared with in-person visits. With telemedicine visits being made from the home, car, and office, privacy concerns, connectivity issues, lighting, and noise are just a few additional factors which may negatively influence diagnosis and treatment and result in poor outcomes (American Hospital Association, 2015, 2016).

Given the variability and challenges of telemedicine, further research is needed to evaluate for diagnostic and treatment concordance comparing telemedicine with in-person visits. Patients, providers, professional societies, and regulatory bodies will need to decide how to balance the convenience of telemedicine with the small, but real, potential for misdiagnosis. Many options exist to mitigate this risk, such as limiting telemedicine to appropriate use cases, using specialized providers, requiring live-interactive video, instituting quality review processes, and ensuring in-person follow-up as appropriate. Even when the quality of the experience and technology are sufficient, telemedicine may further promote episodic care which may in some situations be in conflict with the patient-centered medical

home. For patients with and without chronic illnesses, pediatric urgent care providers can help mitigate this concern by maintaining bidirectional communication with primary care providers and always sending complete documentation of encounters.

Economics and Reimbursement

One of the major barriers to telemedicine continues to be reimbursement, especially given the added costs of equipment and software. Over the past several years, there has been significant progress in reimbursement, with the US Centers for Medicare and Medicaid Services adopting rules that support telemedicine, increasing private payer coverage, and states passing parity reimbursement laws (American Hospital Association, 2015, 2016). Nevertheless, the economic viability of DTC telemedicine is still far from secure, as reimbursement is not consistent across payers and typically is equitable with similar in-person visits.

While, in many ways, DTC telemedicine may be more convenient for both patients and providers, there are some aspects that may be more burdensome and costly for UCCs. Many telemedicine systems have limited or no integration with electronic health records, thereby requiring UCCs to obtain and operate two systems. In addition, current utilization of DTC platforms is often low. UCCs may need to invest significant start-up costs for technology and personnel for a model of care that has yet to see significant patient volumes. Albeit, some of the staffing costs can be offset by using providers who are also seeing in-person visits.

Licensure and Credentialing

Licensure and scope of practice, which historically have fallen under state jurisdiction, vary and add complexity both from a legal and a regulatory standpoint. The Federation of State Medical Boards has created a multi-state compact license agreement for physicians, with 17 states recognizing the compact. The National State Board of Nursing Council has a similar compact for advance practice registered nurses, however with only two states recognizing it. The lack of a national compact is costly and creates challenges with interstate practice, prescribing, and regulations.

Separate and equally frustrating for many providers is the process of becoming credentialed at organizations and hospitals, preventing cross-organization telemedicine in many situations.

Other Challenges

Technical issues, training, provider and patient adoption also continue to be obstacles. Lack of reliable connectivity, broadband capacity, and system integration add to the complexity of implementing telemedicine. Telemedicine equipment should be easy to use, supporting a simple interface for providers and patients, and needs to be accompanied by appropriate and adequate training. Problems with the system, firewall, connectivity, bandwidth, and signal strength should be supported in real-time to enhance provider and patient connections (Walsh, McClain, & Kasinadhuni, 2015).

Interfacing with the electronic health record, ordering tests outside of the system, sharing results, and communicating with the patient's medical home are all additional challenges.

While some education programs do exist to train providers and telemedicine assistants, they are few and their quality and structure vary considerably.

How to Learn More: Available Resources

Many resources are now available for providers and organizations seeking to start or improve a telemedicine program. The American Telemedicine Association (ATA) is a membership organization that has published telemedicine guidelines (American Telemedicine Association, n.d.-a), a state-by-state analysis of policies and laws (American Telemedicine Association, n.d.-b), and has regular conferences and webinars (American Telemedicine Association, n.d.-c). The Center for Telehealth and e-Health Law provides guidance regarding legal and regulatory telemedicine issues (Center for Telehealth and e-Health Law, n.d.). The US Department of Health and Human Services' Health Resources and Services Administration for the Advancement of Telehealth funds 14 Telehealth Resources Centers, 12 of which are Regional Centers and 2 of which are National (Office for the Advancement of Teleheath, Health Resources and Services Administration, Department of Health and Human Services, Telehealth Resource Center, n.d.). One of these National Centers, the Center for Connected Health Policy, also publishes a state-by-state analysis of policies and laws (Center for Connected Health Policy: The National Telehealth Policy Resource Center, n.d.). The AAP and American College of Emergency Physicians each have subgroups that focus on telemedicine and electronic mailing lists that may be of interest to pediatric urgent care providers (American Academy of Pediatrics, n.d.; American College of Emergency Physicians, n.d.).

Summary

Telemedicine for pediatric urgent care is relatively new and will likely evolve rapidly in the coming years. Little evidence to date exists regarding the safety and accuracy of telemedicine specifically for pediatric acute care. Telemedicine has several advantages including reduced costs and improved access, convenience, and efficiency. Nevertheless, telemedicine does pose several challenges, such as quality, privacy and security concerns, fragmentation of care, the inability to easily share data, and the lack of an in-person level physical exam. These challenges need to be addressed carefully and thoroughly as the role of telemedicine continues to evolve. Given the consumer and health system's increasing interest in telemedicine, it is imperative that those who champion the cause of high quality pediatric urgent care also champion the development of high quality telemedicine models.

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Chapter 12
Improving Self-Management and Care Coordination with Person-Generated Health Data and Mobile Health

Katherine K. Kim, Sakib Jalil, and Victoria Ngo

The Rise of Person-Generated Health Data and Mobile Health Applications

Person-generated health data (PGHD) is information about a person relevant to health that is purposefully created by the individual, observed by her, or passively collected by devices about her. Examples of common forms of PGHD in the past include forms for gathering individual's health and family history, screening tools for symptoms and moods, or logs tracking medication use.

In the last decade, we have witnessed a rapid convergence of interest and use of mobile health (mHealth) (Miller & West, 2009). With the availability of inexpensive wireless sensor networks (Alemdar & Ersoy, 2010; Varshney, 2005), increasingly available connectivity, and consumer-adoption of smartphones, opportunities abound for improvements in health management. Paper tools have been replaced by online tools and mobile applications. The diversity and depth of biometric PGHD that can be captured has grown with the availability of devices such as wearable fitness monitors and smartphone accelerometers. These devices can capture data on physical activity, sleep patterns, and heart rate.

Other health data that were customarily collected in clinical settings are today more easily generated by individuals via personal-use devices such as mobile electrocardiograms for detecting heart rhythm, glucose meters for measuring diet related blood glucose levels, and blood pressure cuffs. In addition, environmental sensors offer highly localized and in-home measures. For example, motion sensors detect an individual's movement around a home. Sensors in a bed or chair can collect mobility data and ambient sensors in the home can measure exposure to air pollution.

K. K. Kim (✉) · S. Jalil · V. Ngo
University of California, Davis, Sacramento, CA, USA
e-mail: KathyKim@ucdavis.edu

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Remote monitoring through PGHD presents one possibility for providing timely and precisely targeted health interventions that reduce the need for costly and burdensome hospital-based services (PricewaterhouseCoopers, 2015). Recent surveys revealed that the public acknowledges the value of PGHD for maintaining their own health: 33% of United States (US) residents are using health-tracking mobile apps and 21% using wearable devices (Gownder et al., 2015).

In the last two decades, the bulk of research in mHealth has been related to demonstrating data collection and display of PGHD to individuals for self-monitoring. One of the first systematic reviews of cell phone voice and text messaging use for health management identified 25 studies showing moderate improvements in medication taking, symptoms, smoking cessation rates, and self-efficacy across 13 different health conditions (Krishna, Boren, & Balas, 2009).

An extensive review of randomized controlled trials (RCTs) involving consumer health informatics applications showed that the key technologies employed were computer applications or web-based applications (Gibbons et al., 2011). Even though the studies used a variety of methodological approaches and varied in quality, they provided preliminary evidence that consumer-oriented technology improved health outcomes in mental health, diet/physical activity, breast cancer, obesity, diabetes, asthma, Alzheimer's disease, and HIV/AIDS.

The advent of readily available consumer smartphones in the form of iPhones (2007) and Android operating system phones (2008) launched a dramatic rise in interest in mobile applications or "apps." The field of mHealth research began to grow substantially, as evidenced by the increase in published scientific literature.

As the number of peer-reviewed papers increased, systematic reviews also began to appear that focus on mHealth apps for single conditions. A recent review of mental health apps found eight papers involving five apps associated with significant reductions in depression, stress, and substance abuse (Donker et al., 2013). Four of these apps involved support by a mental health professional.

In studies of heart failure, Creber et al. found that only 3 out of 34 apps that centered on symptom monitoring and self-care in peer-reviewed publications had been evaluated (Creber et al., 2016). In their review of 21 studies using mobile phones for type 1 diabetes, Holtz and Lauckner (2012) found that some showed evidence of improved self-efficacy, hemoglobin A1c, and self-management, with study limitations including insufficient sample sizes and short intervention periods. Similarly, a review of mobile apps for behavior change through self-monitoring found evidence of user acceptance of apps, although most studies involved small sample sizes (Payne, Lister, West, & Bernhardt, 2015).

A body of evidence is also accumulating in cancer care. In a review assessing behavior change techniques utilized in cancer apps. Dahlke et al. found that among 68 apps and games the majority of iOS apps (67%) and about a third of Android apps (38%) used theory-based behavior change techniques (Dahlke et al., 2015). Another review found 594 papers related to 295 cancer apps found in app stores for four major smartphone platforms (Bender, Yue, To, Deacken, & Jadad, 2013).

These reviews reflect the rapid growth in the number of health-focused apps and increasing interest among mHealth researchers in identifying and assessing applications with potential to health people with particular health conditions. However,

most of the apps have not yet been evaluated systematically. There are significant ongoing challenges in understanding what measures were important in the selection and evaluation of apps, e.g., features and functions, behavior change, or health outcomes, in order to build the evidence base that supports what apps work for which conditions and populations.

The Evolution of Self-Monitoring Tools: Examples from Type 2 Diabetes

Type 2 diabetes (T2D) is a chronic condition that affects the way the body metabolizes sugar (glucose), which is the body's primary energy source. T2D is currently one of the world's fastest growing diseases; the prevalence of T2D rose from 171 million affected in 2000 to 415 million affected in 2015 worldwide (International Diabetes Federation, 2017). The total annual global health expenditure for diabetes in 2015 was $673 billion in US dollars, accounting for 12% of the world's total health expenditures. As of 2016, the total global cost is $825 billion per year (Harvard School of Public Health, 2016).

People with T2D either have a resistance to the effects of insulin, a hormone produced by the pancreas that regulates the flow of sugar into your cells, or aren't able to produce enough insulin to maintain a normal blood glucose level (mayoclinic.org). While there may be a genetic component to T2D, there is clear evidence that environmental factors such as excess weight and sedentary lifestyle are contributors.

Individuals living with T2D often need a complex set of services and support including daily glucose monitoring, insulin and other medication management, lab tests, foot exams, and regular medical check-ups. Intensive management of blood glucose levels, through medical intervention or lifestyle adaptations (improved diet and increased exercise), can reduce complications in T2D.

Health information technologies have been used in T2D management since 1990. New technologies emerge rapidly in the consumer market. However, technologies that are applied in US healthcare or medicine must go through regulated testing and evaluation processes, including clinical trials such as those required by the US Food and Drug Administration (FDA) agency in order to be approved for clinical use. For this reason, this section focuses on tools for T2D that were evaluated in randomized clinical trials (RCTs).

Technologies used and evaluated in RCTs of T2D over the last two decades range from basic technologies where patients and clinicians communicate through phone, email, or SMS (short message service) text to advanced web-based frameworks that require connection to the Internet and mobile devices (Jalil, Myers, & Atkinson, 2015). In the 1990s before the Internet, widely available technologies included glucometer modem transfer of data followed by graphical report generation (Shultz, Bauman, Hayward, Rodbard, & Holzman, 1991). Three primary types of technology were reviewed by Jalil et al. (2015): telephone-based, computer-based, and handheld (see Fig. 12.1).

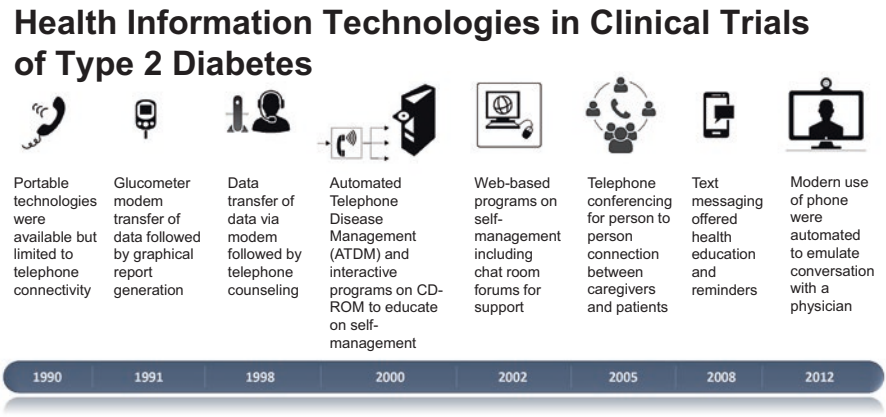

Fig. 12.1 Health information technologies used in type 2 diabetes have evolved over two decades. Source: Katherine K. Kim

Telephone-Based Monitoring Tools

Telephones have been used in many different ways for T2D management. Two early examples are data entry using touch tone telephones followed by voice messages from clinicians (Meneghini, Albisser, Goldberg, & Mintz, 1998) and the transfer of data via modem followed by telephone counseling (Biermann, Dietrich, & Standl, 2000). Another example is the Automated Telephone Disease Management (ATDM)—a telephone-based system where patients received calls at predetermined times and listened to self-management tips navigated via the telephone keypad (Piette et al., 2000).

After the year 2000, non-automated telephone services were also used with basic conferencing via teleconferencing, using person to person telephone connections between caregivers and patients (Izquierdo et al., 2003). Further variation of telephone-mediated and proactive call center treatment support was seen in a telephone-based system where patients spoke with trained non-medical operators (Young et al., 2005). More recently, an RCT used automated phone calls to emulate conversations with a physician (Williams et al., 2012).

Computer-Based Monitoring Tools

While the majority of the clinical trials in mobile health have evaluated telephone-based technologies, some involved computer-based tools particularly in the pre-Internet era. One early example used interactive programs on CD-ROM to educate consumers on self-management of type 2 diabetes (Glasgow & Toobert, 2000). The

post-Internet era saw the emergence of web-based programs on self-management including chat room forums for support (McKay, Glasgow, Feil, Boles, & Barrera, 2002), computer appliances that integrated data from devices such as iCare and the Health Buddy device (Cherry, Moffatt, Rodriguez, & Dryden, 2002), web-based diabetes management systems (Montori et al., 2002), and the Internet Based Glucose Monitoring System (Cho et al., 2006).

Handheld Monitoring Tools

For more than 20 years, handheld portable devices have allowed for patient mobility and convenience in recording time, date, and blood glucose levels (Rutten, Van Eijk, de Nobel, Beek, & Van der Velden, 1990; Tsang et al., 2001). Text messaging using mobile phones then began to offer health education and reminders such as "Please, decrease the long acting insulin by two units," "Please add one tablet of sulfonylurea in the evening," "Lack of exercise may be the cause of the aggravated glucose level," and "Your glucose control seems to be good" (Kim & Kim, 2008).

Mobile Applications in Clinical Trials

Mobile applications ("apps") are software programs installed on mobile devices such as smartphones and tablets with a mobile operating system such as iOS or Android. These apps are equipped with computing and connectivity capability. With the rapid growth in wireless connectivity and smartphone sales, users have access to many different health apps. In the iTunes App Store for iOS and Google Play for Android apps, diabetes is one of the top-ranked categories with more than 1100 different apps available for download (Wu et al., 2017).

However, there is a dearth of evidence about their efficacy or effectiveness. A recent systemic review (Whitehead & Seaton, 2016) showed there were only five randomized controlled trials assessing apps in diabetes self-management. Yet, there is great interest and hope that apps can help people manage their condition. The American Diabetes Association (ADA) guideline states that apps may be a useful element of effective lifestyle modification to prevent diabetes (American Diabetes Association, 2017).

As technologies have evolved in the consumer market, health researchers have begun to study these new technologies and evaluate clinical outcomes. This section reports only T2D health information technologies that were reviewed through clinical trials. The contrast between the number of commercially available apps and the number of RCTs of apps demonstrates a clear need for additional research to help individuals and clinicians and patients determine whether to use apps and how to choose safe and effective ones among the thousands that are available.

Early Research on PGHD and Mobile Health: Examples from Project HealthDesign

One major effort to move mHealth and PGHD forward was Project HealthDesign: Rethinking the Power and Potential of Personal Health Records, which began in 2006 (Robert Wood Johnson Foundation, 2015). Project HealthDesign sought to stimulate innovation and expand the use of technologies to put actionable health information into the hands of patients by awarding $9.4 million to 14 interdisciplinary teams. This initiative introduced the term "observations of daily living" (ODLs), which indicated that much of the data for health decisions was generated by and used by patients themselves in their daily activities, and consequently lack of ODLs might hamper patients' ability to optimize their health (Brennan, Downs, & Casper, 2010).

The Project HealthDesign teams demonstrated innovations that addressed the needs of diverse populations. Here are four examples.

The Estrellita project sought to enable self-monitoring of the health of premature infants and their mothers and deliver those ODLs to clinicians (Cheng, Hayes, Hirano, Nagel, & Baker, 2015).

The Living Profiles: Transmedia Personal Health Record Systems for Young Adults project used principles of design thinking to understand the needs of adolescents with chronic illness related to health information display (Park, Chira, Miller, & Nugent, 2015).

Dwellsense demonstrated how aggregated data from sensors on furniture and pill bottles could provide insights to elderly people about potential cognitive impairment and medication adherence, as well as offer early warning signs to their healthcare teams (Lee & Dey, 2015).

iN Touch demonstrated the value of an application for self-tracking for youth with overweight/obesity and at risk for depression within a health coaching program (Kim, Logan, Young, & Sabee, 2015). The next section provides an in-depth description of iN Touch.

iN Touch: A Mobile Self-Monitoring System and Health Coaching Program

Obesity is a pressing issue that exacerbates the development and ongoing management of chronic conditions and health disparities. Innovative approaches in prevention, treatment, and self-management are needed to stem the rise of these negative health impacts on population health. Obesity disproportionately affects low income and minority teens (Rossen & Schoendorf, 2012; Skelton, Cook, Auinger, Klein, & Barlow, 2009). Adolescent depression is also a risk factor for development and persistence of obesity (Goodman & Whitaker, 2002).

Motivational interviewing-based health coaching shows promise as a method of supporting self-management in chronic illness and its risk factors, such as overweight/obesity (Lindner, Menzies, Kelly, Taylor, & Shearer, 2003). For youth, coaching and coping skills training can impact metabolic risk associated with type 2 diabetes (Grey et al., 2009). Several studies suggest that adolescents find goal setting, action plans, and self-monitoring to be attractive features of a web-based or in-person health coach (Appel et al., 2011; Olsen & Nesbitt, 2010; Thompson, Cullen, Boushey, & Konzelmann, 2012. In addition, there is a growing body of literature indicating that computer-based and mobile behavioral interventions show moderate impacts on diet, exercise, and weight in youth (Cushing & Steele, 2010; Nollen et al., 2013).

Kim et al. report on the iN Touch study, whose purpose was to evaluate acceptance of a mobile self-management application and health coaching by low-income youth with overweight/obesity and assessing the potential for the intervention to affect health outcomes (Kim et al., 2015). The iN Touch application and intervention strategy were developed with participatory methods engaging a ten-member youth advisory board. A 6-month pre-post pilot study was conducted. Urban youths age 13–24 who were overweight or obese, and identified from three clinics in San Francisco (two clinics in the same hospital and one school clinic) that serve primarily low-income patients, were recruited for the study. Participants were provided an iPod Touch with trackers for exercise, food, mood, and socializing, supplemented by photos and notes, (Fig. 12.2) and they met with a health coach.

Summative evaluation of iN Touch encompassed both technology and health domains, see Table 12.1.

These results suggest that technology was accepted by participants who reported that both the application and health coaching are useful for self-management. Health impact based on waist measures and PAM were positive.

Sarah's Story (Box 12.1) offers one example of the broader impact this program had on participants.

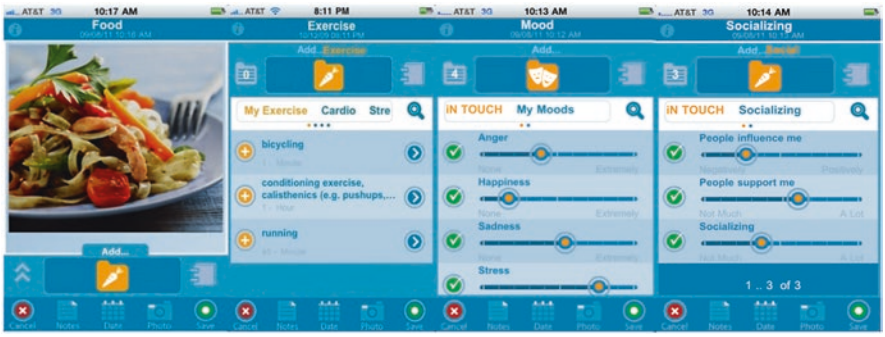

Fig. 12.2 Screenshots of iN Touch self-tracking application supports in the moment awareness of observations of daily living. Source: Katherine K. Kim

Table 12.1 Evaluation of the iN Touch study examines multiple health and technology domains (Katherine K. Kim)

Domain	Evaluation	Significant results
Waist circumference	Paired *t*-test of pre- and post-measure	$M = -1.21$ in., SD = 2.62; $t(22) = -2.21$, $p = 0$
Patient activation measure (PAM)	Paired *t*-test of pre- and post-measure	$M = 0.42$, SD = 0.93; $t(24) = 2.20$, $p = 0.04$
Application usage	Number of ODLs recorded	2117 total over 6 months ODLs/participant/day, $M = 3.11$
Application usefulness	Rating on scale of 1 = low to 5 = high	$M = 3.50$, SD = 1.18
Ease of use of application	Rating on scale of 1 = low to 5 = high	$M = 3.83$, SD = 1.27
Perception that application had an impact on health	Rating on scale of 1 = low to 5 = high	$M = 3.50$, SD = 1.18
Usefulness of application without health coach	Rating on scale of 1 = low to 5 = high	$M = 2.83$, SD = 1.19
Usefulness of health coach without application	Rating on scale of 1 = low to 5 = high	$M = 3.13$, SD = 1.19

Box 12.1: Sarah's Story

Sarah (a pseudonym) was a 214-pound, pre-diabetic high school student who hated comments her peers made about her appearance. When she first met the iN Touch health coach, Sarah shared that she regularly ate fast food, drank soda, and cut class. She wanted to focus on eating healthier and exercising. Sarah and the coach discussed different types of exercises and worked together to create backup plans in case she was unable to do her intended exercise.

Sarah planned to record her observations of daily living (ODLs) about her food, exercise, socializing, and mood in the iN Touch application a few times a week. She began recording her ODLs and found it was easy enough to do. She also used the notes section to intensively journal about her path to a healthier life. Sarah texted the health coach and took advantage of in-person coaching visits to talk about her challenges, strategies, and progress. She also continued to see her regular physicians and nurses.

By the third month of participation she reported that she was cutting fewer classes. She now regularly power walks with hand weights and started taking dance classes over the summer. She has eliminated fast food, chips, and sodas from her diet. Instead, she carries healthy snacks in her purse and drinks only water. At the end of 6 months of participation, Sarah has lost more than 20 pounds.

Sarah's size is not the only change. "I have confidence," she says, "I feel this is my year. Now if people want to come at me with drama, I'm just like, 'I don't care.' I'm going across that stage. I'm going to a 4-year college. Twelfth grade is my serious year."

Source: Kim (2011). Reprinted with permission of author.

Project HealthDesign provided a corpus of studies at the leading edge of science in PGHD and mHealth as it related to observations purposefully collected by individuals about their health. Learnings from these studies demonstrated impacts on health, technology adoption, and feasibility of integration into patient–clinician interactions.

PGHD and Mobile Health for Care Coordination

As mHealth has burgeoned, so has the amount of PGHD available for use by individuals and their healthcare teams. Alongside this growth has been increasing interest in how PGHD can be combined with clinical data to support collaboration among individuals and their healthcare teams and develop new insights to improve care.

The value of PGHD for individuals can be enhanced by leveraging it to enable care coordination across multiple conditions. Care for individuals with chronic conditions such as diabetes or heart disease, or conditions requiring life-long surveillance such as cancer, is complicated and fragmented. Individuals frequently transition between settings: from home to physician office, clinic, outpatient service, emergency department, inpatient hospital, and community-based services.

Due to lack of integration by the healthcare system, the burden of coordinating between the healthcare teams attending each of these settings often falls to the patient, their family members, and close friends (family team). Examples of care coordination activities that family teams conduct are numerous. They may keep copies of important medical records such as consultation reports, recent lab or imaging results, and hospital discharge summaries to share with other clinicians because those records may not be available by the time of subsequent visits. The family team may keep a calendar of appointments and contact list of healthcare providers and facilities in paper or on their phones to facilitate scheduling and rapid communication among the family team members. Finally, they may keep an ongoing list of questions and concerns about medication interactions or side effects, dietary restrictions, or treatment plans without being certain which of their clinicians can offer the answer.

The community-wide care coordination conceptual framework seeks to elaborate the context surrounding an individual's health journey (Kim, Bell, Reed, & Whitney, 2016). This framework shows that there are dynamic relationships and workflows among different teams involved in care of an individual—family teams, healthcare teams, and community teams—and over time (see Fig. 12.3). Different teams, represented by the multi-colored spheres, are involved with an individual (large oval) throughout their health lifecycle. The size of the spheres indicates the magnitude of involvement in any particular stage. Finally, where spheres touch or overlap represents a "point of need" at which coordination is required to synchronize and share information, organize activity, hand-off responsibility, or make

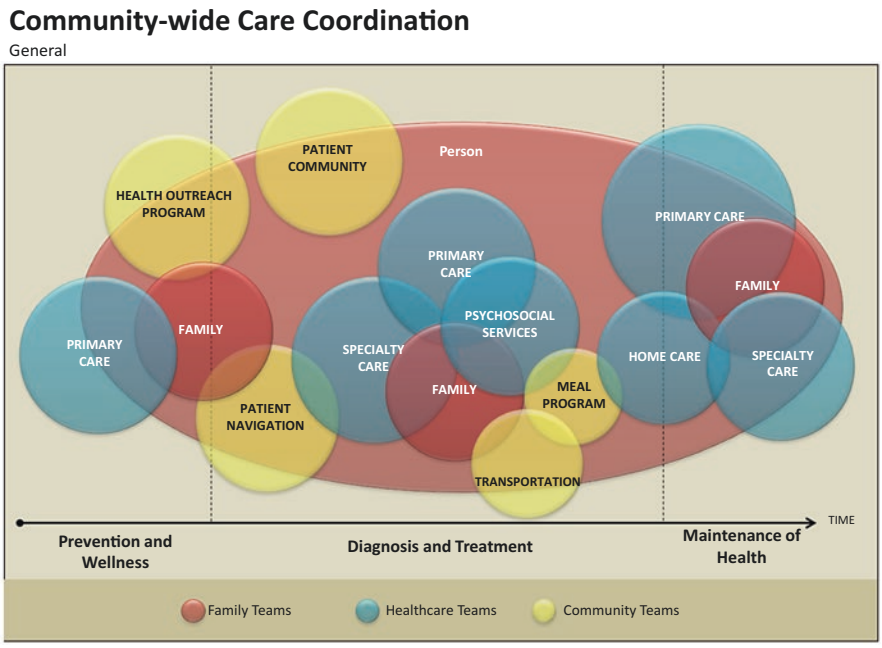

Fig. 12.3 A conceptual frame for community-wide care coordination offers a broad view of a person's health journey. Source: Katherine K. Kim

shared decisions about health. Points of need are broader and more diverse than the points of care where healthcare services are provided.

A shared care plan (SCP) is defined as a comprehensive, evidence-based plan of care that is collaboratively developed with participation of the patient, family, and health care team (Osborn, Squires, Doty, Sarnak, & Schneider, 2016). The SCP is a key tool for care coordination by serving as a means of compiling who, what, when, where, and how care will be accomplished for an individual and communicating that to all parties involved, thus offering a means of assuring that important activities are accomplished. While there is no consensus about the optimal SCP, a starting point for its construction based on a review of published literature identifies both PGHD and clinically generated information (see Table 12.2) (Hsueh et al., 2017).

Few examples of SCPs or other care coordination systems exist for chronic illness or cancer that engage healthcare teams across multiple practice settings with individuals and family teams exist (Kim, Bell, Bold, et al., 2016). The Personal Health Network (PHN) is one example from the authors' research that seeks to demonstrate the value of a mobile technology to enable community-wide care coordination. The PHN is a personalized social network built around a patient for collaboration with clinicians, care team members, carers, and others designated by a patient, to enable patient-centered health and healthcare activities across a relevant community. User-centered design methods were used in several phases of work to

Table 12.2 Informational elements of a shared care plan suggest any types and purposes for person-generated health data

Content categories	Person-generated health data	Clinical data
Contact information	• Patient preferred contacts.	• Responsible clinician. • Number(s) to call for results.
Health history	• Detailed health concerns. • Allergies.	• Conditions, diagnoses. • Health status evaluation populated with computable, standardized data.
Goals and preferences	• Patient's goals. • Expectations of care. • Challenges and concerns. • Self-management capabilities. • Family or caregiver resources. • Patient-reported health status. • Advanced directives. • Patient likes and dislikes.	• Problem list. • Clinical goals. • Treatment plans.
Actions	• Self-tracking measures (e.g., blood glucose, weight). • Tracking of observations of daily living. • Patient self-management plan/behavior change action plan. • Side effects and symptoms. • Tracking SCP items.	• Appointments. • Interventions and treatments. • Test results. • Tests and orders pending at discharge/transfer. • Responsible individual for follow-up. • Evidence-based guidelines. • Tracking SCP items.
Health education	• Identified learner for education if patient is unable to receive it. • Information about health condition.	• Clinical instructions given to patient.
Medications	• Medication concordance and adherence plan and tracking. • Over the counter medications. • Medications that are not being taken.	• Prescribed medications. • Medications during hospitalization. • Pre-admission medication list. • New discharge medications with start date, duration, route, dose, frequency, date, indication.

conceptualize the application, develop the system, and conduct early evaluation of its usability (Kim et al., 2014; Kim, Bell, Bold, et al., 2016).

The resulting PHN system offers both PGHD (proactive symptom assessments, person-reported outcomes, ad hoc questions sent as secure messages, personal notes) and data generated by the healthcare team (appointments, referrals, team member contacts, results of symptom assessments after nurse review, patient education library linked to results of symptom assessments,) allowing for whole person-centered care and collaboration among teams. Figure 12.4 shows several screens from the functioning application rendered on a tablet computer.

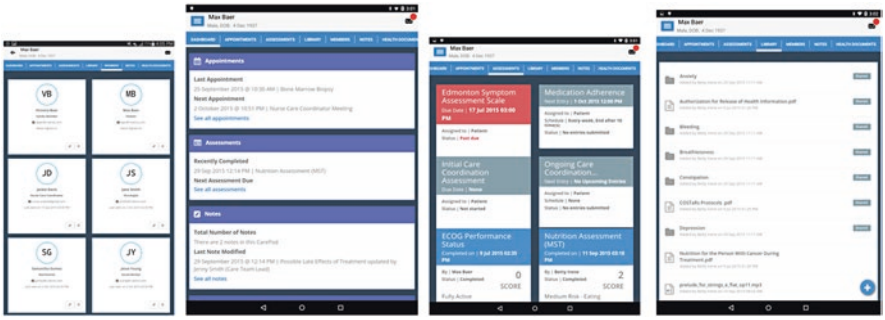

Fig. 12.4 The personal health network mobile application v2.0 integrates PGHD and clinical data including members, patient dashboard (overall care plan), symptom assessments, and patient-reported outcomes. Source: Patient Education Library in Kim, Bell, Bold, et al. (2016)

To meet the needs of a dynamic health journey, the PHN is easily configurable to add/hide individual team members. The instruments used for structured PGHD collection are also easily revised or replaced and can be scheduled at intervals or set for one-time collection. The library can include both educational materials selected by the healthcare team or customized with resources uploaded by the person. Finally, an individual can maintain his or her own notes, upload health records, and share these with others to foster communication across teams.

The PHN is being tested in a randomized clinical trial with evaluation that includes impacts on utilization (ED use and admissions), quality of life (e.g., pain and symptoms), and technology acceptance and use. Although care coordination is not new, the use of PGHD and mHealth to enable care coordination is an emerging area ripe for innovation, adoption, and investigation.

Growth of Persuasive Technology Research

Persuasive technologies (PT) are designed to influence attitudes, behaviors, and choices. This emerging, multidisciplinary field expands on evidence from behavioral sciences, cognitive science, and behavioral economics and uses smartphones, social media, and other digital technologies to influence personal decisions in a variety of areas, including health and wellness.

A recent empirical review of PT research (Orji & Moffatt, 2018) shows that researchers in 21 countries have studied a variety of health behaviors. There is a substantial corpus of research on design of persuasive technology interventions for motivating healthy eating habits (Orji, Mandryk, & Vassileva, 2012; Orji, Vassileva, & Mandryk, 2013). Some examples of serious games using persuasive strategies include: video games for health (Thompson et al., 2008), mobile games to help adults choose healthy meals (Grimes, Kantroo, & Grinter, 2010), LunchTime—a goal-based slow-casual game that educates players on how to make healthier meal

choices (Orji et al., 2013), and Squire's Quest targeted at fourth grade students to influence fruit and vegetable consumption (Cullen, Watson, Baranowski, Baranowski, & Zakeri, 2005).

The effectiveness of PT is variable across health and wellness behaviors and attitudes and includes studies promoting healthy, desirable behaviors and changing undesirable ones (Orji & Moffatt, 2018). However, there is great potential in using PT to improve healthy living, reduce health care costs, and support independent living for older adults (Chatterjee & Price, 2009). By ethically engaging in collaborative design with end-users, and evaluating and refining technologies through user experience testing, we believe PT is very promising and should be further studied.

One promising area for persuasive technology intervention in telemedicine is beneficial for diseases like T2D where behavioral management is key. People living with diabetes need strict control of their blood glucose levels by balancing food, exercise, and insulin (or medication) (Kanstrup, Bertelsen, Glasemann, & Boye, 2008). To teach and motivate changes in eating behavior the persuasive techniques could be an initial recommendation to inform diabetes patients of good food and food to avoid. Motivation and awareness to build better habits for exercise and medication could also be accomplished through persuasion.

For example, just-in time messages or triggers can be set up with the appropriate device reminders to take insulin injection or medication. Persuasive in-home monitoring can make the management of blood glucose levels timely and provide an efficient day-to-day management of diabetes to prevent complicated stages. HIT interventions for behavior change have been identified as a major cornerstone for changing dietary behaviors (Lau et al., 2007). A study in the USA of over 17,000 patients enrolled in a home telehealth program reported a 20% reduction in hospital admissions and 25% reduction in bed days of care for chronic health condition management (Darkins et al., 2008). Recent work has theoretically explored the promises of persuasion techniques if added in existing telemedicine type 2 diabetes in-home monitoring interventions (Jalil, 2013). Research in Australia also has shown promises of integration of persuasive technology with health information technologies (Jalil & Orji, 2016).

Challenges and Recommendations

As the use of PGHD and mHealth continues to expand and evolve, we face several key challenges to adoption.

Challenge: Behavioral Models for mHealth

mHealth itself is a health intervention. The technology and data cannot be divorced from the behavioral model underlying the intervention.

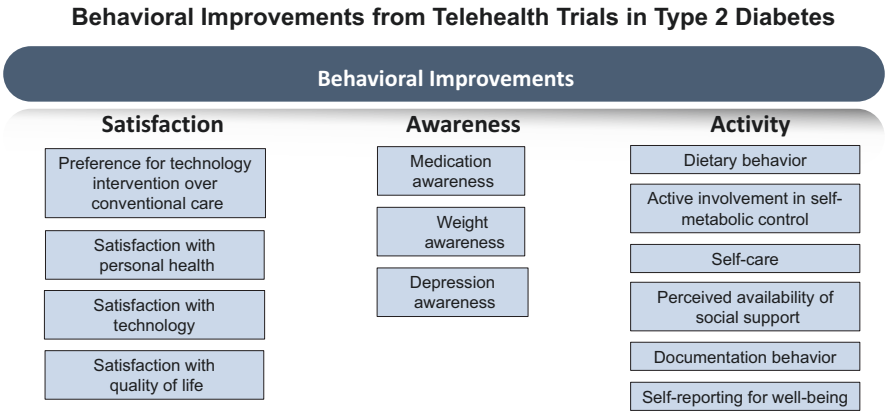

Fig. 12.5 Behavioral improvements from telehealth trials in type 2 diabetes suggest outcome measures. Source: Katherine K. Kim

A major challenge exists in understanding and building technology that is concordant with an appropriate behavioral model and care delivery model. These models help to elucidate not only *what* works to improve health but also *why and how* those impacts are accomplished, thus contributing knowledge that can further enhance the field.

The trials in T2D described in the previous section concluded that technology supports positive behavioral change which may then lead to desirable health outcomes. Three specific behavioral improvements of the patients were seen in these trials: activity improvement, awareness, and satisfaction (see Fig. 12.5) (Jalil et al., 2015). *Activity improvement* refers to activities that the patients adopted due to the technology intervention. *Awareness improvement* refers to the informed state-of-mind about living with T2D that the patients achieved after using the telemedicine intervention. *Satisfaction* refers to the participants' pleasure and fulfillment from using the technology intervention.

These categories of behavioral outcomes help specify *what* the intervention is seeking to improve and also drive the selection of measures of effectiveness. They also contribute to a model through which we can test whether and how these variables contribute to the end goal of improving health.

Recommendation: Understand and Apply Behavior Change Theory

It has been widely reported that health interventions are more effective when based on behavior theory (Ammerman, Lindquist, Lohr, & Hersey, 2002; Glanz & Bishop, 2010; Glanz, Rimer, & Viswanath, 2008; Noar, Benac, & Harris, 2007). For

example, Webb, Joseph, Yardley, and Michie (2010) conducted a systematic review and assessed the use of theory in 85 randomized trials of Internet interventions. The review showed that overall, theory-based Internet interventions showed very small but statistically significant improvements in health outcomes over those not based on theory.

By applying a "use of theory" score calculated as an aggregate of 11 intervention-related items, Michie and Prestwich (2010) found that greater use of theory to select or develop intervention techniques, to select constructs, or to select participants was associated with larger effect size in post-intervention behavior differences. The most frequently used theories in this review were Theory of Planned Behavior (TPB), Transtheoretical Model (TTM), and Social Cognitive Theory (SCT).

In sum, mHealth interventions that seek to change behavior and impact health should leverage the large body of knowledge on health behavior that has been generated in the fields of psychology, public health, and clinical health research.

Challenges: How to Understand and Apply Persuasive Technology Strategies

The study of how to design technology to motivate behavioral change has been of increased interest to researchers and industrial practitioners due to the widespread uses of technology such as computers, mobile phones, and iPad. Fogg (2002) led the way to persuasive technology as "a computing system, device, or application designed to change a person's attitude or behavior in a certain way" without using coercion or deception. Oinas-Kukkonen extended the idea that technology is never neutral; it influences users in one way or another (Oinas-Kukkonen & Harjumaa, 2009). However, the influences occur as "side effects" of technology use, rather than the planned effect of the technology design (Fogg, 2002).

On the contrary, persuasive technology is designed to intentionally target a specific behavioral change of the users. The persuasive system design model (Oinas-Kukkonen & Harjumaa, 2009) posits that a multitude of aspects need to be recognized when designing persuasive systems: responsiveness, error-freeness, ease of access, ease of use, convenience, information quality, positive user experience, attractiveness, user loyalty, and simplicity, to name a few. This model also addressed precise requirements to translate the ideas from theory to the system design of the technology.

Even though the use of PT is not effective at all times, there is an increasing interest and investments to develop and use technology to promote health and wellness. Researchers, practitioners, governments, technology designers, public health agencies are all working towards similar goals and deploying technologies for health and well-being. PT research has a great potential to be one of the solutions for a healthy world.

Recommendation: Design the Right Solution

We must design solutions well to meet users' needs and accomplish their health objectives. However, it can be challenging to understand in detail what users' needs are and translate those needs into system requirements. Research on how to design technology to influence a behavioral change has been of increased interest to researchers and industrial practitioners due to the widespread uses of technology such as computers, mobile phones, and tablets. In order to accept mHealth, at a minimum, users must perceive mHealth technology to be reliable for health purposes.

Technical challenges such as lost messages (Holtz & Lauckner, 2012), poor battery life, freezing of apps, and connectivity challenges that are not tolerable in general consumer-facing apps are also unacceptable in mHealth (Donker et al., 2013). Technology is not neutral; it influences users in one way or another (Oinas-Kukkonen & Harjumaa, 2009). Unreliability due to technical issues may have a negative influence on adoption for obvious reasons.

Given the dynamic and inter-connected nature of health, team communication and features for discretion in sensitive health-related communications are necessary but all too often neglected (Bender et al., 2013; Donker et al., 2013; Payne et al., 2015). We need methods to leverage technology as a positive influencer and tool for individuals to improve health.

Challenge: How to Promote Technology Adoption

Understanding how the content, system, and service of an intervention are used and experienced may be the key to understanding why HITs suffer from large non-adherence rates. Efficacy and effectiveness studies through randomized trials are important, but they should be complemented by, for example, qualitative methods or measures of the usage of HIT interventions to be able to understand why and how these interventions do or do not achieve the desired effects.

Despite the proliferation of mHealth in the past decade, research on the effectiveness, utility, and technical and financial feasibility in real-life clinical settings is still lacking (Holtz & Lauckner, 2012; Krishna et al., 2009). There are numerous challenges related to implementation such as keeping up with technology, accommodating technology, competing priorities, technical compatibility, patient privacy, complicated partnerships, complicated technologies, clinician resistance, fitting technologies into clinical practice were challenges identified with personal health records (Brennan et al., 2010).

In a systematic review focusing on patients' acceptance of telehealth technologies, Dinesen et al. (2016) concluded that focusing on patient factors alone was not sufficient for understanding the degree of patients' interest (or lack of interest) in using telehealth technologies. Yet, existing literature focuses largely on patient-related factors such as sociodemographic characteristics, health- and treatment-related variables, and prior experience or exposure to computer/health technology.

Studies rarely examine the impact of social and task factors on acceptance or the effects of organizational or environmental factors on acceptance (Or & Karsh, 2009).

PGHD and mHealth appear promising for improving health. But the hoped for impacts will not be realized unless these new interventions and enabling technologies are adopted by the intended users.

Recommendation: Understand and Apply Technology Adoption Models

Several models for technology adoption with measurement scales can be helpful in design and implementation of mHealth. One of the foundational instruments for technology adoption is the ten-item Computer Self-Efficacy Scale (CSES) developed by Compeau and Higgins (1995) which focuses on beliefs of employees about ability to competently use computers.

The Technology Adoption Model which combines technology acceptance (Davis, 1985) and technology motivation (Davis, Bagozzi, & Warshaw, 1992) probes a person's belief in their ability to respond to situations and deal with obstacles in the process of accepting technology in a workplace setting (Venkatesh, Speier, & Morris, 2002). Recent work by several researchers has adapted the Technology Adoption Model to understand consumers' and patients' use of technology (Or et al., 2011; Venkatesh, Thong, & Xu, 2012). Venkatesh's instrument specifies constructs that may help pinpoint problems that deter adoption or levers that improve adoption (see Table 12.3).

Table 12.3 Emerging technology acceptance and use constructs focus on interaction of people and tools

Construct	Definition
Performance expectancy	Perceived benefit: Degree to which using a technology will provide benefits to consumers in performing certain activities. Concept of utility/extrinsic motivation. Strongest predictor of intention (Venkatesh, Morris, Davis, & Davis, 2003)
Effort expectancy	Perceived ease of use: Degree of ease associated with consumers' use of technology (Venkatesh et al., 2003)
Social influence	Extent to which consumers perceive that important others (family and friends) believe they should use a particular technology. More important in mandatory settings (Venkatesh et al., 2003)
Facilitating conditions	Consumers' perceptions of the resources and support available to perform a behavior (Venkatesh et al., 2003)
Hedonic motivation	The fun or pleasure derived from using a technology (Brown & Venkatesh, 2005) intrinsic motivation
Price value	Consumers' cognitive trade-off between perceived benefits of the applications and (their own, not third party) monetary cost for using them (Dodds, Monroe, & Grewal, 1991)
Habit	Extent to which individual believes behavior to be automatic (Limayem & Hirt, 2003). Construct important to use rather than initial acceptance

Technology adoption encompasses more than just usability. How the technology is implemented within a clinical trial or a health intervention is crucial to its potential acceptance. Investigations of interactions between the patient and the technology are important because failure to use a technology by patients or an adverse response to the technology from patients can cause patients to withdraw from a clinical trial. With the advent of several models and their associated instruments, there are tools to assist in more deeply understanding individuals' use of health technologies.

Conclusions

Technology is not a goal in and of itself. Rather technology is complementary to and increasingly necessary for a health delivery model that takes into account what individuals value and how they behave.

There are many unexplored questions in the quest to design and evaluate efficacious and effective health interventions enabled by PGHD and mHealth. The challenges outlined in this chapter may seem daunting and the breadth of expertise needed begs for unprecedented collaboration across fields both within and outside of health. However, there are innovative approaches that have emerged that are ripe to be applied to these challenges.

Behavioral models and behavior change theory have been extensively studied in health psychology-related disciplines but have not been well-integrated with mHealth. Technology adoption models help us to understand the interaction of the person with the environment and context of use while persuasive technology approaches inform the design of the technology. Learning from the work of pioneers and early researchers who have integrated behavioral models with technology adoption and persuasive technology are illustrative of the caliber of work and resulting innovations that are possible from interdisciplinary systems thinking.

Contributions from numerous fields can benefit the conceptualization, design, development, and implementation of PGHD and mHealth solutions and optimize the potential for accomplishing health objectives. Teams representing expertise from human factors and computer engineering, human computer interaction, design, health informatics, healthcare practice, community health, behavior change should collaborate with potential users and stakeholders in the success of these technologies. The opportunities for innovation through these teams abound not only for new researchers but also for practitioners who will bring solutions into our health institutions and the communities where people live.

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Chapter 13
Behavioral Medicine and Informatics in the Cancer Community

Ellen Beckjord, David K. Ahern, and Bradford Hesse

Introduction: The Cancer Care Crisis

The IOM estimates that new cancer cases will reach 2.3 million by 2030, a marked increase over the 1.6 million new cases anticipated in 2014 (American Cancer Society, 2014). Cancer is a complex disease requiring interactions with multiple healthcare service providers and demand for services that can be costly to administer (Balogh, Patlak, Nass, National Cancer Policy Forum (U.S.),, & Institute of Medicine (U.S.). Board on Health Care Services, 2013; Patlak et al., 2011). The complexity of the disease can create inefficiencies in the handoffs between the many professionals needed to diagnosis the disease, to prescribe and administer treatment, to support post-treatment survivorship, and in terminal cases to negotiate hospice and end-of-life care (Taplin & Rodgers, 2010).

In the USA the cost of cancer care is rising faster than any other sector in medicine, with economic analyses showing an increase from $72 billion spent on cancer care in 2004 to $125 billion spent in 2010; and a projected increase of another 39% to $173 billion by 2020 (Balogh et al., 2013; Levit, Balogh, Nass, Ganz,, & Institute of Medicine (U.S.). Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, 2013). The presence of comorbidities expands the number of healthcare providers servicing cancer patients, thus further escalating risks for inefficiencies and discontinuity

E. Beckjord (✉)
Insurance Services Division, University of Pittsburgh Medical Center, Pittsburgh, PA, USA
e-mail: beckjorde@upmc.edu

D. K. Ahern
Digital Behavioral Health & Informatics Research Program, Brigham & Women's Hospital, Boston, MA, USA

B. Hesse
Health Communication and Informatics Research Branch, National Cancer Institute, Bethesda, MD, USA

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(Hesse, Hanna, Massett, & Hesse, 2010; Kohn, Corrigan, & Donaldson, 2000; Tinetti, Fried, & Boyd, 2012).

Finally, the IOM projects a marked shortfall in the number of trained professionals to deal with the impending surge in cancer cases in the years to come (Levit et al., 2013), meaning fewer health care providers will have to do more to meet the demands of the growing population of people diagnosed with and who survive cancer. For these individuals, their journeys can continue to be fraught with confusion, frustration, and fragmentation (Hewitt, Ganz, Institute of Medicine (U.S.), and American Society of Clinical Oncology (U.S.), 2006). Survivors struggle with the transition as they move back into the primary care environment, but yet must carry the burden of fears of recurrence, secondary cancer, or even the risk of late-term side effects from their cancer treatments.

The Indispensable Role of Informatics

As the IOM has repeatedly affirmed, the promise of advances in cancer care cannot be enabled without significant participation from the informatics community (Nass, Wizemann,, & National Cancer Policy Forum (U.S.), 2012; National Research Council (U.S.). Committee on A Framework for Developing a New Taxonomy of Disease, 2011; Olson, Institute of Medicine (U.S.). Roundtable on Translating Genomic-Based Research for Health., and Institute of Medicine (U.S.). Board on Health Sciences Policy, 2012). Participation is needed to create the technologies needed for collecting and processing the vast amounts of information needed to inform clinical decision making in close to real-time, to create a distributed platform for sharing information with multiple members of a patient's care team, to improve quality of care delivery, to inform research, and to empower patients.

Improving the quality of cancer care ultimately requires reengineering the healthcare environment to support better outcomes for the many dedicated healthcare workers who operate within the system. The objective must be to create a new care environment that is by design safe, effective (i.e., adherent to evidence), patient-centered, timely, efficient, and equitable across all patient populations. Because medicine is inherently an information-based science, Health Information Technology (Health IT) is a necessary platform upon which to achieve this goal (Institute of Medicine (U.S.). Committee on Quality of Health Care in America, 2001; Levit et al., 2013; Reid et al., 2005). Health IT can be used to reengineer care processes, support a more timely and effective workflow, serve as a platform for evidence implementation, collect data on care effectiveness as input to quality improvement efforts, and could be used to help connect and coordinate the expanding list of specialized services needed to treat patients over their lives (Institute of Medicine, 2012; Levit et al., 2013).

Health IT Adoption from the Consumer's Side

The Health Information National Trends Survey (HINTS)

In 2001, following the inflection point of the first "dot com" speculative bubble, the NCI launched a general population survey called the Health Information National Trends Survey, or HINTS. Its purpose was to give behavioral researchers and communication planners access to population data on how Americans 18 years or older accessed and utilized information relevant to cancer control and prevention in a rapidly changing information environment (Nelson et al., 2004).

Anecdotally, program planners had heard stories of patients walking into their primary care and oncology care offices with "reams of printouts" from the World Wide Web related to their conditions. The NCI wanted to know, first, if people were indeed flocking to new electronic media outlets for cancer information and, second, how well were people able to utilize the information and channels they encountered in this new environment to prevent disease, adhere to treatment, or maintain personal vigilances as a cancer survivor.

The first administration of the national probability sample was fielded as a Random Digit Dial telephone survey in 2003, with the second administration occurring in 2005. For the third administration, in 2007, the program split the sampling frame into a newly announced postal frame for paper-and-pencil administration in one arm to be compared with the traditional RDD sampling approach. A fourth administration was begun in 2012, with four cycles of the survey conducted in succession over the course of 3 years (Finney Rutten et al., 2012).

HINTS began by tracking public access to the Internet in 2003 with a question asking if respondents had "gone on-line to access the Internet or World Wide Web, or to send and receive e-mail" (Hesse et al., 2005). In 2003 HINTS documented a 63% penetration rate for adults 18 years and older, which languished in 2005 down to 61% following the dot.com implosion, but then increased steadily to 68% in 2008, 78% in 2012, and 80% in 2013. Also, in 2003 HINTS began tracking where people reported going first when looking for information about cancer (from the subset of people who said that they had looked for cancer information from any source). The estimated percentage of individuals who reported going to the Internet first (of those who looked for cancer information) in 2003 was 48%. That number has climbed steadily up to an estimated 78% who went online first to look for cancer information by 2012.

About 65% reported that, to their knowledge, they believed their healthcare providers were already utilizing a system to exchange patients' health information electronically. By 2013, those numbers rose to 68% and 88%, respectively. It is interesting to note in this case that the general public's perceptions of their provider's utilization of EHRs may have exceeded percentages of actual implementation as described earlier.

Taken together, these data suggest an increase in demand from the general public for health services that can be provided through electronic means. Not surprisingly,

consumers are accustomed to making travel reservations online or checking their bank accounts online, but when it comes to checking their personal health information that capacity has been limited.

Phase 2 of the *meaningful use* incentive program (Blumenthal, 2010) sought to address this discrepancy by requiring attesting hospitals to show that 5% of their patient base had gone online to engage in their health information during the qualifying period. Patient engagement has been identified as a core component of high-quality healthcare for patients with chronic disease, especially given the often-cited observation that the success of treatment depends heavily on patient adherence and vigilance about managing their disease. Data confirm that patients who are disengaged in their own health care are "the toughest group to manage and account for a disproportionate share of healthcare costs" (Kvedar, Coye, & Everett, 2014).

The Internet of Things (IoT)

There has been a proliferation in the market place of consumer-facing applications and mobile devices designed to promote health. US smartphone owners are using mobile health apps downloaded from the health and fitness categories of online app stores. Other innovations include extensions of support through the "Internet of Things," to create environmental supports for at-home care while nudging healthy behaviors.

One commonly cited example is the development of "smart scales" that can transmit weight data into smartphone apps, and eventually even into EHRs, as a way of helping patients engage in active weight management. Another example is the implanted cardiac defibrillator received by cancer survivors with cardiotoxic secondary effects from chemotherapy. Wireless versions of these devices can be engineered to send signals to the cardiologists for remote monitoring, but are still not often engineered to deliver self-management back to patients.

New devices are also under development to help with improved adherence and monitoring for cancer patients taking home-based oral chemotherapies by utilizing wireless signals from transponders placed in pharmaceutical bottles to track drug intake and body temperature sensors to achieve early identification of fever that can warn of serious complications like neutropenia. The Food and Drug Administration (FDA), the Centers for Medicare and Medicaid Services (CMS), and other regulatory agencies are investigating the use of these sensors to save costs through reimbursements for telemedicine and at-home care.

Creating Deep Support for Engaged Patients

By emphasizing the goal of making a system that is patient-centered, the IOM has reiterated a common theme: that the focus of systems reengineering efforts should be on creating an underlying foundation of deep support for patients, their families,

and the professionals who care for them (Institute of Medicine, 2011; Institute of Medicine (U.S.). Committee on Quality of Health Care in America, 2001; Levit et al., 2013; Reid et al., 2005). This is particularly critical for people affected by cancer, especially as patients and their families are encouraged to cope with their disease by taking a more active role in their own care (Cayton, 2006).

Our research has involved speaking directly to cancer survivors about their thoughts regarding the role of Health IT in their care. We heard their hopes for the ways informatics can improve the lives of people affected by cancer, but we also heard their frustrations over seeing how many well-meaning supports do not seem to help but may actually hinder their ability to take care of themselves or a loved one. Here is how one patient described the information overload s/he experienced while trying to cope with a complex care regimen:

> Patient 1: "Because when you're a patient, and you're sick, and you don't feel well, and you're tired, and you're taking 10 medicines or whatever it is, you don't have time to read 40 pages of discharge [notes]."

That sentiment speaks to the importance of user-centered design, and the promise of health IT to deliver the right information, to the right person (in a language they can understand) at the right time (Finn & Bria, 2009; Shneiderman & Plaisant, 2010). This may seem far-off for IT in healthcare settings, but it is not far-off from what patients have come to expect when interacting with the ubiquitous tools that enrich lives—from searches on the Web for information on any facet of their lives, including health and cancer; to making their own travel reservations online; or even interacting effortlessly with a GPS (geographic positioning system) that puts all of the mathematic calculations behind the scenes as it presents terabytes of localized data easily through an intuitive interface.

In a similar vein, here is how two patients described their view for how Health IT can help them and help their providers get a more coordinated, personalized view of their own health conditions.

> Patient 2: "You know, when you have EMR and can go out and look things up in a way that makes sense to an individual care provider … whether it's blood work or former radiologists' reports, and even the actual images themselves, you give them a quicker, better way to really understand you as a patient without either having to try and remember it on your own or for them to try and piece it together."

> Patient 3: Nobody … and I can say this truthfully … in the last two years-nobody is looking – except one physician who happens to be in the room– none of them are looking at the others' [clinical notes]. And I do resent that…when it is something that is right there in front of them. Even if it's their physician extender be it PA, be it a nurse-doesn't matter … It is maddening, it is frustrating, and to the point that now I'm saying, "Enough."

Notice how these patients' views paralleled observations from the report commissioned by the National Research Council (NRC) titled *Computational Technology for Effective Health Care: Immediate Steps and Strategic Directions.* Based on observations of systems in action, authors of the NRC report called for interdisciplinary research to solve challenges in three critical areas: "(a) organizational systems-level research into the design of health care systems, processes, and

workflow, (b) computable knowledge structures and models for medicine that help care teams make sense of all available patient data including preferences, health behaviors, and so on; and (c) human-computer interaction in a clinical context" (Stead & Lin, 2009).

Moreover, a fourth patient emphasized the fact that we are no longer engaged in a solely academic exercise in informatics—with time to spare for slow, glacial translation of proven principles into the care system. With success in the consumer market around so many other facets of their daily lives, consumers are getting impatient with the slow progress in bringing them into their own care more effectively through technology. These were some of the lessons we learned in poring over the HINTS data. Patients and the general public were flocking to the Internet first, before being able to visit their providers, while hoping to interact with their providers in convenient ways online (Hesse, Moser, & Rutten, 2010).

We were emboldened to see in 2012 and again in 2013 that the majority of American adults already thought that their providers were making use of EHRs to share information, and that a majority also set a high priority on being able to get their own data electronically. The fourth patient captured the upcoming surge of patient demand this way:

> Patient 4: "And yet the influx of new patients, I mean, they're more [tech] savvy than I'll ever be, and they're gonna demand it [i.e., access to their care through health I.T.]."

Health IT has an indispensable role to play in cancer care. The future has never looked brighter—or more challenging—for behavioral medicine and informatics in the cancer community. Whether we reach new heights or allow challenges to stall progress will depend, in large part, on the effective use of Health IT. In the remainder of this chapter, we will review three areas of behavioral medicine and informatics across the cancer continuum, including near time of diagnosis (informatics and screening for distress); during treatment (informatics to facilitate clinical communication); and after treatment (informatics in survivorship care planning).

Role of Behavioral Medicine and Informatics in Distress Screening

Behavioral science as applied to health and disease has a rich history and robust portfolio of evidence (Fisher et al., 2011). The growth of behavioral medicine as a professional specialty of behavioral science applied to the study of behavior, health, and disease coincided with the evolution of the personal computer and technology revolution of the last 40 years. In many ways, both behavioral medicine and technology have matured to a point where there is a unique opportunity to integrate these two domains to help solve the complex and intractable societal problems, including the crisis in cancer care, that adversely impact the health of our nation.

Pagoto and Bennett (Pagoto & Bennett, 2013) provide a compelling rationale for the critical role for behavioral/psychological science and behavioral medicine in

advancing digital health and informatics. They propose five key areas in which behavioral/psychological science can impact digital health technologies: (1) research to determine which health technologies actually impact behavior and health outcomes, (2) evaluation studies to understand how evolving online social networks can be applied to health behavior change on a large scale, (3) emphasis on a team science approach to the developmental process of health technologies, (4) achieving a desirable balance between the fast pace of innovation and the slower pace of research, and (5) promoting the role of behavioral scientists as integral in informing the development of digital health technologies and their inclusion into the health care system.

Central to their argument is that behavioral/psychological science adds value through demonstrating the most effective feedback strategies for tailoring, methods to improve participant engagement and utilization, creation of scientifically sound application rating systems, and enhancing the impact of digital health technologies through inclusion of evidence-based, behavioral strategies.

Similarly, Ahern, Woods, et al. (Ahern, Woods, Lightowler, Finley, & Houston, 2011) provide a framework for organizing patient-facing technologies into categories of how these technologies can improve health care quality, safety, and population health. Growing patient demand for information and "convenience services" has stimulated a variety of HIT-enabled functions designed to maximize patient participation, including services that allow patients to conduct health-related transactions, increase access to professionals and electronic health record (EHR) information, and support self-care management. As predicted by behavioral theory, those technologies that patients perceive as useful and which are effective in terms of sustained health behavior change in their target domain are likely to be adopted and used.

Screening for Emotional Distress and Unmet Needs

In 2008, the Institute of Medicine published a report, "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" (Institute of Medicine, 2008). Its authors argue that oncology's focus on extending life often comes at the expense of quality of life, and call for greater attention to patients' emotional distress, for instance, depression and anxiety, and unmet needs, for example, lack of resources or knowledge to manage illness.

The IOM document fueled a then nascent psychosocial screening movement, which has since rapidly expanded, frequently on an electronic platform. In 2015, as a new requirement for accreditation, the American College of Surgeons (ACoS) Commission on Cancer (CoC) began requiring cancer centers to implement comprehensive screening programs for psychosocial distress, leaving many institutions unprepared to institute and universalize psychosocial screening, as well as the triage processes that follow from it.

In general, instruments querying emotional symptoms focus on the domains of anxiety and depression. The most common instruments used in screening for emotional distress include the Generalized Anxiety Disorder Symptom 7-item (GAD-7) with cutoff scores for general anxiety disorder as defined by the DSM-5; the Patient Health Questionnaire-9 (PHQ-9) with cutoff scores for major depressive disorder as defined by the DSM-5; and the Hospital Anxiety and Depression Scale (HADS) and Psychosocial Screen for Cancer (PSSCAN) in which case finds for both depression and general anxiety. By contrast, other instruments are designed to identify nonspecific "distress" rather than a DSM-5 psychiatric diagnosis.

The most well-known is the one-item National Comprehensive Cancer Network (NCCN) Distress Thermometer. When such a screen is employed, additional evaluation to clarify diagnosis is warranted. Because social stressors—financial, family, or work pressures—and physical symptoms such as pain or dyspnea often mediate emotional symptoms, other screens or components of screens query unmet needs. Perhaps the best known of these is the NCCN Problem List, which is a companion to the NCCN Distress Thermometer and covers family, practical, and spiritual concerns along with psychological and physical symptoms.

A variety of strategies to meet the psychosocial screening mandates and best serve the "whole patient" have been pursued. Some institutions rely on health providers to interview patients directly; others employ pen-and-pencil self-reports. However, because staffing is at a premium and timely review of screens can be critical for the addressing of severe psychiatric distress or urgent unmet needs, electronic screen administration with instantaneous scoring is likely preferable to both options, particularly since several electronic systems now boast flagging of worrisome scores; tracking over time; automated triage capabilities; and provision of educational materials to providers and patients (Bower et al., 2014). In recent years, several homegrown systems have been developed and a few commercial entities, for instance, Polaris Health Solutions, have developed both screening platforms and applications.

Implementing Psychosocial Screening: An Informatics-Based Approach

As the mandate for psychosocial screening is implemented in centers throughout the country, it will be essential to have a plan in place to evaluate and treat distress. Studies have indicated that screening alone is not adequate for addressing sources of distress and improving patient outcomes (Carlson, Groff, Maciejewski, & Bultz, 2010; Gilbody, Bower, Fletcher, Richards, & Sutton, 2006). Psychosocial screening needs to be part of a more comprehensive approach that includes further assessment and identification of the source of distress, referral to appropriate services, and initiation of evidence-based treatment (Carlson, Waller, Groff, & Bultz, 2013; Lazenby et al., 2015).

Forsythe and colleagues (Forsythe et al., 2012) conducted a population-based study to identify how many cancer survivors discussed their psychosocial concerns with their health care providers and whether the survivors received psychosocial care services (defined as professional counseling or use of support groups). Results from this study identified that only 40% of patients reported discussion with their health care providers about their psychosocial concerns, 4.4% received psychosocial services only, and 8.9% reported both discussion with their health care providers and use of psychosocial services. Thus, this study provided important information about the implementation of psychosocial care on a population level.

As these services are implemented on a larger scale, a potential problem may be lack of an adequate number of qualified professionals to address patient psychosocial needs. Although most cancer care settings offer a range of psychosocial services to patients, many centers have fewer than three psychosocial providers (Deshields, Zebrack, & Kennedy, 2013) available to provide these services. Thus, innovative solutions are needed to prepare for the anticipated demand for services and to deliver high-quality, evidence-based psychosocial care to cancer patients.

One potential partial solution is the use of evidence-based algorithms for non-behavioral health providers to choose appropriate psychotropic medication for treatment of depression and anxiety in the oncology setting. Passik and colleagues (Passik et al., 2002) conducted a pilot study and demonstrated that oncologists can be empowered to recognize and treat depression with a "screen and intervene" approach using a paper-based algorithm for choosing an antidepressant treatment. Moreover, patients experienced improved mood and health-related quality of life (HRQOL).

The SAMI System

Informatics-based approaches have a high potential to help fill the gap and create population-based approaches to augment delivery of psychosocial care. One example of an informatics-based system that has potential to enhance psychosocial and palliative care through clinical decision support is the SAMI program. Cooley and colleagues (Cooley et al., 2013) created computable algorithms for management of multiple symptoms, which included depression; anxiety; pain; fatigue; and dyspnea, based on national guidelines for use in an outpatient thoracic oncology setting. These algorithms were part of a web-based program that provided point-of-care clinical decision support to health care providers to enhance symptom assessment and management.

The SAMI system comprises four components: (1) collection of patient-based symptom assessment data (patient-reported outcomes [depression, anxiety, pain, fatigue, dyspnea, comorbidities, laboratory values, prescribed medication] that were actually taken and their dose and frequency); (2) guidelines in the form of algorithms that provide CDS for symptom management; (3) a web-service decision engine known as the System for Evidence-Based Advice through Simultaneous

Transaction with an Intelligent Agent Across a Network (SEBASTIAN); and (4) a summary report for health care providers.

The *symptom assessment* component uses a web-based survey platform developed by Dana-Farber Cancer Institute for collecting PROs using validated instruments such as the PHQ-9. This application delivers questionnaires with capacity for scoring weights and skip logic and stores the answers in a MySQL database. In the prototype, laboratory, medication, and comorbidity data are manually entered in a graphical user interface (GUI), but may be imported from an EMR in the future. The clinical decision logic is derived from guideline-based algorithms for symptom management that were adapted from national guidelines and then programmed into SEBASTIAN.

Decision rules were implemented in SEBASTIAN using an object-oriented computer programming language (Java). SEBASTIAN's web-services framework provides a scalable, system-agnostic approach to integrating knowledge into clinical practice. SEBASTIAN can receive requests for CDS capabilities from remote systems. In these requests, patient data are represented in eXtensible Markup Language (XML) format and encoded using standard terminologies. As a result, decision logic can be centralized in SEBASTIAN for use by many systems at different sites, which enables the sharing of computable knowledge across remote locations.

To generate care recommendations, four main steps are followed: (1) upon the clinician's request the SAMI client application retrieves the patient's symptoms, medications, and laboratory values from the patient database; (2) the patient data are transformed into the SEBASTIAN XML format (Kawamoto & Lobach, 2005); (3) the client application submits a web-service request to a server that hosts an instance of SEBASTIAN; (4) SEBASTIAN executes a series of symptom management rules over the provided data and responds back to the client application with a set of recommendations also in XML format; and (5) the client application parses the XML recommendations and presents them to the clinicians in the SAMI user interface as a summary report consisting of text and graphics. SAMI provides tailored suggestions for evidence-based symptom management and a longitudinal summary of symptoms experienced over time.

In a feasibilty study in patients with advanced lung cancer and their clinicians, SAMI met requirements for successful implementation in settings of care (Cooley et al., 2015). Patient completion of the symptom assessment was 84% over time and delivery of the reports to clinicians was 90%. Clinician adherence to the recommendations was 57% (95% CI 52–62%). Management of depression, anxiety, and palliative care consults for pain were more likely among the clinicians randomized to SAMI as compared to usual care.

The convergence of behavioral/psychological science and technology affords enormous opportunities to address the increasing burden of cancer prevention and control. The future success of oncology informatics is predicated on drawing from the best available scientific evidence from biomedicine and behavioral sciences as complementary resources.

Communication Science: Connecting Systems for Health

Communication science, as it is used in this chapter, refers to the interdisciplinary mix of theory and empirical evidence that contributes to a more informed understanding of how humans convey information to each other across multiple channels, in multiple contexts, and in differing time frames to achieve desired goals. In the context of health, communication assumes a vital role in "informing, influencing, and motivating individual, institutional, and public audiences about important health issues" (Parrott, 2004).

This is perhaps most challenging in the context of cancer. As long-time leader and advocate in the fields of patient engagement and cancer survivorship Dr. Jessie Gruman put it;

> "Those of us with multiple chronic conditions may consult many physicians in the course of a year. Last year, I saw 11. Not one of my doctors has ever communicated directly with another, despite the fact that some of them work in the same health system and have offices in the same building. I am the sole arbiter of who gets what information in what format and when."(Gruman, 2011)

Early models of health communication emphasized the role of mass media as a unidirectional channel for elevating awareness and motivating action. With the diffusion of Internet technologies, those models have expanded to encompass the one-to-one, one-to-many, many-to-many, and cognitively augmented capacities of computer-mediated communication channels (Kreps, 2010; Kreps & Neuhauser, 2013). Indeed, because of its centrality to health the US Office of Disease Prevention and Health Promotion included a separate objective within its Healthy People 2020 initiative on the topic of "health communication and health information technology."

One way to think about the process of communication in the context of an informatics-enabled cancer care system is to consider the inter-defining attributes that comprise any instance of communication activity (Hesse, Werner, & Altman, 1988). In this conceptualization, communication processes can be viewed as occurring within and across specific *environments*, as occurring between specific *people* or actors, and as having identifiable *temporal* qualities. We consider each of those dimensions below.

- The *environments* in which cancer communication may unfold can include face-to-face conversations within the clinic or, in a mediated sense, can occur over a telephone or smartphone as one party engages in a virtual consultation with the other. An informatics intervention will usually allow health systems designers to reengineer the communication environment to achieve more effective care, or to save time and money by economizing on the use of expensive clinical settings. For some applications, the informatics structures may serve as the medium through which interaction occurs. In others, they may serve as a prompting mechanism to trigger face-to-face interactions as needed by the patient or patient's family.

- The *people* component of the communication may be restricted to the patient and oncologist, or the interaction could be broadened to include members of an interdisciplinary care team on the health care provider's side, or significant others and caregivers on the patient's side. We have included the psychological processes that govern behavior and decision making as an integral aspect of this people-related aspect of communication. As we shall see, many eHealth applications were designed using behavioral theory to augment the cognitive processes underlying effective decision making or to nudge behavior toward a desired, healthier goal.
- The *temporal* attribute of the framework is included to acknowledge that all communications unfold over time, and that time matters when it comes to thinking about disease processes and preemptive care. Temporal qualities include the scale of the interaction, expressed as a duration for interactions that occur over a short (e.G., acute) or longer (chronic) time frame; the sequencing of interactions over time, or the order in which events can or should unfold; the pace of the interaction, that is the slowness or rapidity of events; and the salience of past, present, or future activities embedded within the communication.

Informatics innovations support improvements to health care processes by offering solutions that reconfigure the profile of these interdefining facets in safer, more efficient, and effective ways (Hesse & Suls, 2011).

Using Communication Science to Improve Quality of Cancer Care

Because medicine is essentially an information science, errors in the transmission of information can prove to be particularly problematic. Information and communication technology would be needed to improve the fidelity of transmission, and to ensure that the right information is delivered to the right person (or persons) at the right time to make a difference (Gary L. Kreps, 2010). Information that is not delivered to the right person, at the right time, or that is miscommunicated through error in its conveyance can lead to poorer outcomes.

To understand how errors in communication can pose a threat to safety and quality improvement in oncology, consider the following case study. In its online case review at *Morbidity and Mortality (M & M) Rounds on the Web,* the Agency for Healthcare Research and Quality (AHRQ) presented the case of a 48-year-old man with a history of metastatic penile cancer who was admitted to an inpatient internal medicine service for a fourth round of chemotherapy. According to the case details, the patient had been admitted three times before—each time with a standard 3-day administration of paclitaxel, ifosfamide, and cisplatin without complication. The patient checked into the internal medicine service for a fourth round of administrations and went through a customary three-day protocol with no incident. On day 4 he expected to be discharged. To his surprise, however, his nurse announced that he

was scheduled to receive a fourth round of chemotherapy. Before receiving this additional dosage the patient asked to see a representative from the oncology care team responsible for directing his treatment. The oncology fellow arrived at his bedside and after talking with the patient and rechecking the orders discovered that there had been a serious error. Rather than ordering a 3-day regimen for penile cancer, the orders dictated a higher dose 5-day regimen of paclitaxel, ifosfamide, and cisplatin for germ cell cancer (Jacobson & Weingart, 2013).

This case is instructive for two reasons. On the one hand, it shows what can happen when simple transcription errors interfere with an oncology team's intended treatment plan. This is a communication error. In the case of cancer care, which the AHRQ site describes as *"dangerous business [because] patients have a potentially life threatening disease and often require toxic therapies,"* the consequences of these types of communication errors can have deadly effects—both to the patient as "first victim of medical error" and to the oncology team who suffers as "the second victim of error" (Edrees, Paine, Feroli, & Wu, 2011).

An accompanying commentary to the AHRQ article was quick to point out that this particular miscommunication could have been avoided if the oncology care team had been supplied with a functioning Electronic Health Record (EHR) to support its processes. As it turned out, a simple transcription error had occurred when hand-copying orders from the patient's chart to the nurse's duty roster. Health Information Technology (HIT) has shown efficacy in ameliorating these types of transcription errors through the use of computerized physician ordering systems (Buntin, Jain, & Blumenthal, 2010).

The Patient Voice

On the other hand, the case also illustrates just how essential the patient voice was in helping to alert the nurse that an error may have occurred in her orders and then to bring that error to the attention of the oncology team for immediate repair. The case embodies the notion that communication is a two-way process; and that when patient care is participatory (Hill, S.,, and Cochrane Collaboration, 2011) and patients are activated (Greene, Hibbard, Sacks, & Overton, 2013), the safety of the healthcare system can be enhanced through self-corrective communication processes (Delbanco et al., 2012).

The Cochrane Collaboration, a global independent network of professionals working to synthesize medical evidence into prescriptions for what works, emphasized this role of communication science in their review titled *"The Knowledgeable Patient: Communication and Participation in Health."* As the authors of the text explained it, consumer empowerment has become the policy focus of health systems and governments over the past 30–40 years. A focus on communication science within health care takes the execution of best practice away from personal intuition and puts it squarely "within the realm of evidence-based medicine" (Weingart et al., 2010).

At first blush, it may seem paradoxical to think that informatics solutions can resolve communication weaknesses in the oncology enterprise; after all, when patients think about good communication they pay particular attention to the observed or inferred affections of their providers. Did the provider team listen carefully to patients' questions, and did they do so with a good "bedside manner" showing sympathy and respect? Do patients report a general feeling of trust and reliance in their care system or do they report an ineffable, general sense of frustration or isolation? These are the questions especially important to patients and their caregivers, and no amount of technology could possibly make up for a surly clinician's attitude or a soulless administrative bureaucracy.

Nevertheless, from a sociotechnical perspective, informatics solutions can serve to augment the communication skills of a well-trained and professional workforce. They can extend the oncologist's reach beyond the walls of the clinic and the temporal constraints of an already crowded workday. Engineered correctly, they can serve to broaden the bandwidth through which virtual members of the extended healthcare and patient team engage in one of the most essential of human activities: *communication*.

Cancer Survivorship

Individuals with a personal history of cancer—referred to herein as "cancer survivors" or "survivors"—number more than 14 million Americans. Over the course of their lifetime, one in two men and one in three women will be diagnosed with cancer (American Cancer Society, 2014). In 1971, when President Nixon declared a "war on cancer," average 5 year survival rates for cancer were only at 51 percent (Rowland & Bellizzi, 2008). Today, the landscape is significantly different: for adults diagnosed with cancer between 2003 and 2009, 5 year survival rates are nearly 70% (American Cancer Society, 2014). Survival statistics are even more favorable for children diagnosed with cancer, as nearly 80% survive for 5 years or longer (Howlader et al., 2014).

For some types of cancer, conditional survival statistics show that after a certain period of time, the history of a cancer diagnosis no longer negatively impacts life expectancy. For most cancers, the likelihood of survival increases with each year the individual survives, and for early stage breast and colorectal cancers, after surviving for between 3 and 15 years, there is no evidence that the diagnosis of cancer contributes to excess mortality in this group compared to cancer-free peers (Janssen-Heijnen et al., 2007).

However, this "booming" population of cancer survivors (Carla Parry, Kent, Mariotto, Alfano, & Rowland, 2011) is still relatively new within the cancer community. The term "survivorship" first appeared in the literature in 1984, when "survivorship" was specifically identified as a topic of importance in nursing research (Carter, 1984). At the founding meeting of the National Coalition of Cancer Survivorship (NCCS) in 1986, the term "cancer survivor" was defined emphatically

and broadly. The NCCS declared "an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life" (Ganz, 2009). This definition, which has been widely adopted, including by the National Cancer Institute, also includes other individuals directly affected by the diagnosis, such as family, friends, and caregivers (Ganz, 2009). Here, we will use the term "cancer survivor" or "survivor" to refer to the individual diagnosed with cancer, and will mostly focus on the time in survivorship that occurs after primary treatment ends.

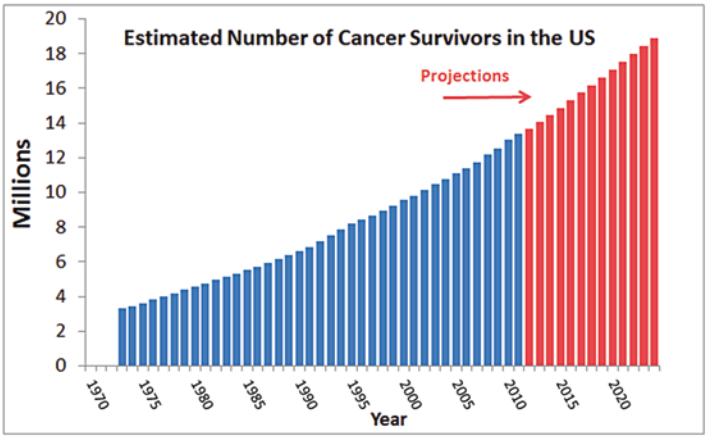
In 2005, the Institute of Medicine (IOM) released a landmark report titled "From Cancer Patient to Cancer Survivor: Lost in Transition" that made a series of recommendations for research and practice devoted specifically to the period of survivorship that occurs after treatment ends (Hewitt, Greenfield, & Stovall, 2005). The IOM's recommendations for survivorship research and practice cover a broad amount of territory, commensurate with the wide array of issues and needs that exist within this population. In general, in the nearly 30 years since the NCCS proposed a definition of "cancer survivor," the research on this population has not caught up to the new definition of the cancer control continuum, and there is a need for more research devoted to primary and secondary prevention among cancer survivors, as well as a need for continued investigations into interventions that are intended to improve survivor health-related quality of life (HRQOL; (Harrop, Dean, & Paskett, 2011)).

All of this has implications for informatics in the context of cancer survivorship. Cancer survivors, like most Americans, are heavily engaged in use of informatics, and even more so in some cases, such as use of the Internet to look for cancer information (Hesse, Arora, Burke Beckjord, & Finney Rutten, 2008).

By 2020, when the population of cancer survivors approaches 18 million (see Fig. 13.1), more than half (63%) of cancer survivors will be 65 and older. This cohort, then, would have been 48 years old in 2003, when, according to the National Cancer Institute's Health Information National Trends Survey (HINTS), roughly 58% of Americans were online, and they would have been 58 in 2013, when HINTS suggested that Internet penetration reached nearly 80% (National Cancer Institute, 2013). As such, the largest age demographic within the growing population of cancer survivors were likely still part of the workforce when the Internet came of age in the USA, and were likely exposed to the Internet in the context of their employment. This suggests that survivors, on the whole, are well-positioned to benefit from use of informatics applications.

Research and practice devoted to survivorship stands to benefit from informatics in a number of ways as well. Survivorship has come to be understood as a highly transitional time when, like other transitions in healthcare, the risk of "falling through the cracks"—whether it be information falling through the cracks or cancer survivors' concerns—is high (Grunfeld & Earle, 2010). Few expect that an exclusively oncologist- or PCP-led model of survivorship care will emerge as a solution to doing a better job of meeting the needs of cancer survivors (Howell et al., 2012).

In this way, if care coordination will be an unavoidable challenge in survivorship care, solving the challenge of care coordination in survivorship care requires a reliable operationalization of the processes for information exchange and establishment



[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

Source: National Cancer Institute's Office of Cancer Survivorship (http://cancercontrol.cancer.gov/ocs/statistics/statistics.html) which cites *DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.*

Fig. 13.1 Number of cancer survivors alive in the USA. Source: National Cancer Institute's Office of Cancer Survivorship (http://cancercontrol.cancer.gov/ocs/statistics/statistics.html) which cites DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press

of accountability that are integral to care coordination. In the 2005 "Lost in Transition" IOM report, the survivorship care plan (SCP), which includes a treatment summary (TS), was first proposed as this operationalization. The IOM report recommended that the SCP includes multiple components addressing treatment history and follow-up care recommendations (Box 13.1).

Box 13.1 Recommended Components of SCPs

- Cancer type, treatments received, and their potential consequences.
- Specific information about the timing and content of recommended cancer follow-up.
- Recommendations regarding preventive practices and how to maintain health and Well-being.
- Information on legal protections regarding employment and access to health insurance.
- The availability of psychosocial services in the community.

Adapted from (Hewitt et al., 2005*).*

Over the past decade, in the wake of the 2005 IOM report, SCPs became, in a way, a beacon of hope for solving the challenges in providing better care to cancer survivors and were identified as the most promising solution to the care coordination challenges in survivorship care (McCabe & Jacobs, 2008). There were multiple calls for specific "transition visits" at the end of primary treatment in which the SCP would be delivered to the cancer survivor, thus demarcating the end of primary treatment and the beginning of survivorship care. The survivor, then, armed with the SCP, would no longer get "lost" in the transition (e.g., (Seehusen, Baird, & Bode, 2010)). As a result, research began to detail the results of the provision of SCPs to cancer survivors. This research has shown that SCPs alone fall short of overcoming the challenges in survivorship care, and that informatics will be key to solving those challenges and realizing the full potential of both SCPs and survivorship care *planning*.

Dr. Carrie Stricker and her colleagues studied the degree to which SCPs provided by LIVE**STRONG** Survivorship Centers of Excellence adhered to the recommendations of the IOM regarding what SCPs should contain, and also how long it took to prepare and deliver the SCP to a survivor. The LIVE**STRONG** Survivorship Centers of Excellence involved multiple academic medical centers that partnered with community settings of cancer care (Shapiro et al., 2009).

Stricker and her colleagues (Stricker et al., 2011) found that, despite the enormous amount of work the Centers of Excellence were putting into SCPs, they were not reliably creating SCPs that included the elements recommended by the IOM (Box 13.1) and that the process of creating and delivering the SCP was not scalable or sustainable. Only 2 of 13 Center of Excellence sites were delivering SCPs that were in at least 75 percent concordance with the IOM recommendations. Over one-third of sites reported that it took more than an hour to prepare the SCP, and 30% said it was more than an additional hour to review the SCP with the survivor. However, of significant note is that Stricker's study focused on activity in the LIVE**STRONG** Centers during 2009, during which few sites could leverage an electronic health record (EHR) to create, deliver, or disseminate the SCP. The lack of an informatics-based foundation for the SCP was likely a major barrier for the Centers to achieving concordance with the IOM recommendations and to creating and delivering SCPs in a more reasonable amount of time.

Additionally, in 2011, Dr. Eva Grunfeld and her colleagues published the first randomized trial designed to gauge the impact of SCPs on survivorship health outcomes in the *Journal of Clinical Oncology* (Grunfeld et al., 2011). For 408 early stage breast cancer survivors who were at least 3 months post-treatment, participants' care was transferred to their PCP upon conclusion of primary cancer treatment, and all underwent a transition visit with their oncology practice. Between 2007 and 2009, women randomized to the intervention group also received an SCP, which was delivered during a 30 min nurse-led visit. Additionally, the SCP was provided to the participant's PCP.

Results showed that the only difference observed between the survivors who received an SCP and those who did not was that slightly more survivors who received an SCP could identify their PCP as being responsible for their follow-up

care. There were no differences observed on any of the other outcomes, and a secondary analysis of the study data showed that the provision of the SCP to the intervention group added $67 to the cost of care and did not result in a significant gain in quality-adjusted life years (Coyle et al., 2014).

Informatics-Enabled Survivorship Care Planning

The Stricker and Grunfeld studies proved that SCPs alone would not be a solution to survivorship care's most pressing problems and that the most promising way forward for survivorship care would require *informatics-enabled* survivorship care planning.

In 2013, in her seminal commentary in the *Journal of Clinical Oncology*, "Can't See the Forest for the Care Plan: A Call to Revisit the Context of Care Planning," Dr. Carly Parry and colleagues (C. Parry, Kent, Forsythe, Alfano, & Rowland, 2013) proposed a conceptual framework for survivorship care planning that emphasized informatics as a foundational component of survivorship care planning. In Parry's framework, technology is positioned as a foundation to models and processes of survivorship care. Informatics-enabled SCPs and survivorship care planning hold incredible promise to significantly improve the survivorship landscape. Informatics is uniquely suited to address two significant barriers to allowing SCPs to reach their full potential.

First, survivorship is a highly individualized experience. The challenges that any one individual encounters during survivorship are a function of their type of cancer, the treatments they received, any pre-existing comorbid conditions they may have had, and their pre-morbid and current socioeconomic status and sociocultural environment. In short, one size will never fit all when it comes to SCPs, so use of informatics to make the personalization of care plans feasible is absolutely necessary.

Second, and related, is that survivorship is a dynamic and heterogeneous journey (Ganz, Casillas, & Hahn, 2008; Stanton, Revenson, & Tennen, 2007). What a survivor needs from their SCP or from the care planning process at one stage of their survivorship journey may be very different from what they need at the next. In this way, unless the SCP that serves as the informational foundation of good survivorship care planning is an evolving, dynamic, "living and breathing" set of recommendations, it will not reach optimal usefulness over time (Feuerstein, 2009; Silver, 2011).

SCPs that use EHRs as a foundation are much better positioned to be agile and nimble in this way. EHR-enabled SCPs are better positioned to stay current with the survivor's needs, so long as the assumption that their current needs are accurately documented in the EHR holds true.

However, there are two major challenges to this assumption: first, the evidence suggests that relatively few survivors receive care for their post-treatment physical, emotional, and practical concerns. Data from the LIVE**STRONG** Surveys of People Affected by Cancer found that among survivors with post-treatment physical

concerns, only 67% received care for their concerns; among survivors with post-treatment emotional concerns, only 47% received care; and among survivors with practical concerns, only 37% received care (E. B. Beckjord et al., 2014). If few survivors are receiving care for their post-treatment concerns, then the process of using the EHR as a reliable foundation for a current take on their needs—which would involve assessment and documentation during a clinical encounter—is not viable. Survivor concerns may be electronically documented elsewhere—in online peer support forums; conversations in virtual support communities; or even in an online record of health status and care received created by the survivor. While valuable, like other kinds of person-generated data, their clinical utility is lost without integration into the broader clinical informatics infrastructure via the EHR.

The second and related challenge to EHR-enabled SCPs has to do with the general challenges of delivering survivorship care. A serious barrier to moving toward standardized models of survivorship care planning and care delivery is that most of the activities involved, including the creation and delivery of SCPs (EHR-enabled or otherwise), are not reimbursable care events, thus discouraging providers from engaging in these activities over and above their already strained schedules (Earle & Ganz, 2012).

Despite these barriers, EHR-enabled SCPs are uniquely positioned to overcome them. A high priority for increasing the frequency with which SCPs are created, delivered to a survivor, and delivered to other providers in the survivor's healthcare ecosystem to support care coordination is to make the process of creating the SCP more efficient and workflow aligned. Here, informatics and the EHR are instrumental. Not only can use of the EHR as a foundation for SCPs and survivorship care planning more broadly help the content of SCPs and care planning evolve and remain current with the survivor's dynamic needs, but an informatics foundation can also significantly increase the efficiency with which SCPs are created (E. Beckjord, 2014). Using the EHR as a foundation, much of the information in an SCP related to the details of the cancer diagnosis, treatment received, and follow-up recommendations can be automatically populated into the EHR, saving time and effort on the part of the provider and clinic staff.

This model was used in one of the only published demonstrations of SCP delivery that actually showed a financial return on the investment of the SCP creation and delivery process. Rosales and colleagues detailed their SCP model with descriptions of how the EHR was used to populate key components of the SCP, leading to the creation and delivery of the SCP occurring in less than 1 h. In addition, they discussed ways of billing for the SCP process and found that after accounting for the time it took to create and deliver the EHR-enabled SCP, that there was an average 6% return on the investment after receiving reimbursement (Rosales et al., 2014).

This likely reflects the future direction of SCP creation and survivorship care planning more generally—using the EHR and other informatics-based systems to largely automate the process of creating the SCP; to keep it current and evolving in tandem with survivor needs; and to share it for the purposes of care coordination with other providers involved in the post-treatment care of the cancer survivor, most notably, their PCP. Achieving this future state will be a significant step forward in

overcoming current challenges related to providers creating SCPs that adhere to the IOM's recommendations as far as what content the SCP should include (Stricker et al., 2011), and to providers sharing and reliably receiving SCPs within the survivor's healthcare ecosystem (Forsythe et al., 2013).

Two studies that specifically focus on EHR-generated SCPs have been done at the University of Wisconsin. Tevaarwerk et al. (2014) examined the provision of an EHR-generated SCP to 38 breast cancer survivors who were between 4 months and more than 4 years post-diagnosis. Using the elements of SCPs outlined by the IOM as the standard, they found that only a minority of elements could be automatically populated in the EHR-generated SCP. However, the electronic infrastructure that supported the SCP allowed for relatively easy manual entry of information, resulting in the median time for SCP creation to be 3 min (range 2–12 min). The EHR-generated SCP was made available to survivors online; 95% found it to be easily accessible and survivors spent, on average, about 12 min reading their SCP.

The second study from this group (Donohue et al., 2015) examined PCP ($n = 72$) reactions to SCPs that were not only generated by the EHR but were delivered to the PCP via the EHR. PCPs responded overwhelmingly favorably to the SCPs, both with respect to content (88% found the information useful and 82% said it supported clinical decision making) and with respect to receiving the SCP via the EHR. In fact, 89% of PCPs said that receiving an SCP via an EHR would be critical to their actually using it in care for cancer survivors.

Scaling the creation and provision of SCPs through EHRs will rely heavily upon data sharing and data liquidity, or more generally, interoperability (for an in-depth review of these issues, please see Kibbe (2016)). Interoperability has proven to be a stubborn and significant rate-limiting step in health informatics, in the context of survivorship and more broadly. While the past several years have seen enormous growth in the degree to which the Internet and other informatics-based tools are being used to document, measure, and track health outcomes, the promise of this growth has largely yet to be realized because of challenges in interoperability.

The Value of Information–Sharing and Interoperability

Lack of interoperability limits the use of informatics in survivorship care planning in two fundamental ways. First, without the data liquidity required to pull clinical data from informatics-enabled medical systems into care planning tools such as SCPs, adoption of SCPs will remain low (Gillespie, 2010). Second, informatics-based SCPs cannot be shared across settings of care if the settings do not use interoperable informatics systems.

The lack of interoperability of health information is particularly troublesome for oncology. The inability to seamlessly share information from one oncology practice to another, or from one cancer center to another, creates serious delays in care coordination and decision making where the stakes are often very high: life or death. The IOM report, *Delivering High Quality Cancer Care: Charting a New Course for*

a System in Crisis (Levit et al., 2013), contends that current Health IT tools and resources are inadequate to address the delivery system challenges, with the lack of interoperability as a major barrier. ASCO acknowledges that this problem has reached a crisis level and has invested significant resources in CancerLinQ (Schilsky & Miller, 2016) to enable data fluidity and create a continuous feedback loop to enable a learning system to emerge.

A number of multi-stakeholder public–private collaboratives have emerged to stimulate and support data sharing to improve quality of care (Jacob, 2015). These organizations and their members also are committed to addressing the issue of sustainability so that information sharing remains a priority and can be consistent with business success and growth.

Practice is slowly catching up to potential. In 2013, Jensen and colleagues reviewed 27 electronic patient-reported outcomes (ePRO) systems used in cancer care (Jensen et al., 2014). ePRO systems capture patient-reported data electronically, such as on a computer, tablet, or mobile device, and are a critical part of an informatics-enabled cancer care system. ePRO processes in cancer care allow for potential integration of survivor (patient)-reported data with the clinical data in the EHR, and when used together, can create a reliable and evolving picture of the survivor's current needs. Jensen's review found that of the 27 cancer care ePRO systems reviewed, 12 were linked to an EHR and five were linked to a patient portal. Clinical integration and actionable reporting structures that make use of ePRO data were noted as continued challenges that have yet to be fully addressed.

Another concern about interoperability relates to privacy and security of personal health information. At the beginning of the millennium, there were robust national conversations around the privacy and security implications of informatics-enabled medicine pointing to concerns among patients and healthcare consumers about the privacy and security of their own health information and reluctance for their personal information to be shared.

But most recently, it seems that while there continues to be broad agreement that privacy and security are critical to the success of informatics-enabled health care, that patients are ready for it and willing to take on any risks informatics might pose, as these risks are less significant than the potential benefits that could be realized when informatics is more broadly and consistently leveraged in medicine (Hoffman, 2010). Data from studies of the Veteran's Administration's (VA) healthcare system (one of the most mature informatics-enabled health care systems in the world) show that the vast majority of veterans (nearly 80%) want others to be able to access their personal health record, including others who are outside of the VA healthcare system, for the purposes of coordinating care (Zulman et al., 2011).

Data from the 2013–2014 administration of HINTS found that fewer Americans were "very concerned" about the privacy or security of their health information being sent electronically between health care providers (about 19%) as compared to health information being shared via fax (about 25%; (Patel, Beckjord, Moser, Hughes, & Hesse, 2015)). HINTS also showed that 84% of Americans believed their health information was kept in electronic format by their health care providers, and that 75% of Americans were confident in the privacy and security of that

information. Further support was found in a 2010 LIVE**STRONG** survey targeted to cancer survivors, where over 70% said that health care providers should be able to share information electronically (Rechis, Nutt, & Beckjord, 2011).

In 2016, the Office of the National Coordinator released the Interoperability Roadmap report (Technology, 2015) which lays out a detailed plan for achieving a fully interoperable health system by 2025. The major goals of this plan are:

1. Send, receive, find, and use priority data domains to improve health care quality and outcomes (2015–2017);
2. Expand data sources and users in the interoperable Health IT ecosystem to improve health and lower costs (2018–2020); and.
3. Achieve nationwide interoperability to enable a learning health system, with the person at the center of a system that can continuously improve care, public health, and science through real-time data access (2021–2024).

A recent paper described a study where a research team visited 11 different EMR vendors in order to analyze their user-centered design (UCD) processes. Not surprisingly, results indicated that there was a diverse range of practices ranging from basic to well-developed in the approach to UCD. The authors concluded that vendors could benefit from studies that provide greater contextual analysis of clinical workflows, encourage enrollment of providers in usability studies, and engage leadership in support of such work (Ratwandi, Fairbanks, Hettinger, & Benda, 2015).

Fully integrated health systems with aligned payment structures (e.g., Kaiser, Geisinger, and Intermountain Health) recognize the potential for combining comprehensive EMRs as clinical data repositories that when coupled with agile, IT-based decision support tools, can enable greater uptake and end user satisfaction as well as more timely and effective clinical decision support (Mandl, Mandel, & Kohane, 2015).

Emerging Trends and Future Opportunities

Building the Future Together

Though we are facing a "crisis" in cancer care described by the Institute of Medicine (Levit et al., 2013), we end feeling hopeful that multiple efforts are underway to equip the health care system to step up to the crisis, and ultimately, avert it. The guidance we have received from consumers in three areas offers important insights into priorities for continued work. They are: using Health IT to reduce the "work" associated with health; using Health IT to benefit others; and using Health IT as a source of support.

The stressors associated with cancer are not only a function of being diagnosed with a life-threatening illness that is accompanied by significant physical, emotional, and practical concerns (Beckjord et al., 2014), but also of having to do manage the information and navigate the medical system that are inevitably part of

one's cancer journey. This has been appropriately characterized as "work" associated with illness (Valdez, Holden, Novak, & Veinot, 2015), and for most people, adding more work to an already busy and fast-paced life is not a welcome addition. Maintaining health even when one is not sick requires a significant amount of work, as many facets of modern American life are not well-aligned with meeting nutrition, physical activity, or preventive health care guidelines.

Reducing the Consumer Burden

Consumers want Health IT to reduce the "work" of health and illness. They expect that Health IT will make it easier for them to acquire, process, and make use of needed health information. They want Health IT to shift the burden of responsibility for communicating their health history and data within their medical records from them to the health care system. They are tired of hand-carrying piles of paper records from one provider to another, and now expect that all providers in their personal healthcare ecosystem should be able to know what the others are recommending.

Making this work more efficient and convenient will not only require consumer-facing solutions that address these issues, but also system-side solutions that support information sharing and care coordination, and continued shifts in policies that make the clinical information consumers desire more available to them (e.g., Delbanco et al., 2010)).

Second, consumers want Health IT to empower them to benefit others. This is largely in the form of sharing their data for the purposes of both research and to lend support and insight to other consumers in a comparable clinical situation. Initially, consumers looked to Health IT to enable sharing their de-identified medical record data to benefit the clinical enterprise. Now that consumers are using Health IT outside of the clinical context to generate clinically meaningful data via the use of health-relevant mobile applications, the "data altruism" movement encompasses an even broader opportunity for consumers to use their data in the service of helping others. While not unique to the cancer survivor community, we note that cancer survivor advocates have been some of the most historically active in finding creative ways to support one another, and expect that survivors will play a significant role in shaping how Health IT can become optimally useful in the service of helping others affected by cancer.

Finally, consumers look to Health IT as a source of support. Cancer, like any life-threatening illness, has the hallmark characteristic of shining a spotlight on the uncertainty that is inherent in everyday life, though easier to ignore when in good health. Health IT stands to ease the anxiety associated with this uncertainty in many ways, including through facilitating the connection of consumers to needed information, to their healthcare team, to others experiencing similar clinical circumstances, and to the family members and friends working to support them. In this way, Health IT can truly serve as a lifeline for consumers. As such, we can come to a new appreciation for the urgency of realizing the full potential of Health IT. Failures

at any level—whether technical, operational, or in implementation—ultimately impact consumers. When facing an illness like cancer, consumers must endure a significant level of vulnerability. One of the most tragic consequences of missteps in Health IT is when Health IT exacerbates this vulnerability. One of its most important roles and potentials is to ameliorate it.

We view this time as just the nascent stage of what will become a mature field of behavioral medicine and informatics in cancer. Much has been accomplished over the last decade but we have much more to achieve to realize the benefits of Health IT and informatics. We remain optimistic that oncology care will improve through the strategic use of Health IT, and believe Health IT will be foundational to a much improved health care system to the benefit of all citizens.

Conclusion

In every way, the future of survivorship looks bright. Survivors will continue to live longer past their time of diagnosis; models of survivorship care will continue to evolve and become more robust and available; and SCPs and survivorship care planning will move closer to achieving their full potential in helping survivors to live well and healthy. Informatics, at every level from the healthcare system to the survivor, will be instrumental to achieving this future. For the large population of cancer survivors that will only continue to grow over time, informatics will be key to optimizing their care and health outcomes.

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Chapter 14
Content Strategy: Writing for Health Consumers on the Web

Carolyn Petersen

Introduction

Health information for the nonmedical audience has been available on the Internet since the mid-1990s. During that time, a majority of adults reported using the Internet for health information seeking (AlGhamdi & Moussa, 2012; Pew Research Center, 2013), and one in three used the Internet to diagnose a health condition (Pew Research Center, 2013). Mobile health applications, which number more than 165,000 (Misra, 2015), also deliver health information to the consumer audience.

In addition, patients and consumers look for health information on social media venues such as Facebook and Twitter, and health care organizations increasingly use social media to reach individuals there (Kotenko, 2013). Patients and advocacy groups have used social media to reach others with similar health concerns for years (Fox, 2014).

Using health information and health information technologies such as mobile health and social media is a primary strategy for improving health outcomes at the individual and population levels (Office of Disease Prevention and Health Promotion, 2017). Clearly written, actionable health information, including online health content, is the foundation of online initiatives to help patients and consumers manage their health.

Of course, consumer health information has been around for a long time in many forms—pamphlets, magazines, booklets, videos and DVDs, and CD-ROMs to name a few—but the principles that define "good" information remain largely the same. No matter the manner of delivery, consumers of health information seek content that is current, clear, concise, and user-friendly. This principle underlies everything you do as a creator of consumer health information.

C. Petersen (✉)
Mayo Clinic, Rochester, MN, USA
e-mail: petersen.carolyn@mayo.edu

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Users of different ages, education levels, socioeconomic status, and other characteristics differ in their ability to comprehend and act on consumer health content. By 2050, more than half of Americans will come from racial or ethnic minority backgrounds (Koh, Gracia, & Alvarez, 2014). Health literacy, the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2000), will continue to be a key concern for content creators as users become more diverse.

Health literacy is one source of the health disparities experienced by racial and ethnic minorities and people with low education (Bennett, Chen, Soroui, & White, 2009; Sentell & Halpin, 2006). Low health literacy has been found to promote negative outcomes in people being treated for asthma, osteoporosis, oral disease, Parkinson's disease, and other conditions (Curtis, Wolf, Weiss, & Grammer, 2012; Fleisher, Shah, Fitts, & Dahodwala, 2016; Holtzman, Atchison, Macek, & Markovic, 2017; Roh, Koh, Noh, Gong, & Baek, 2017). People with low health literacy have reported poorer general and physical health and greater stress (Stewart et al., 2015).

Even well-educated people, such as those with a professional degree, may be lacking health literacy (Bakker, Koffel, & Theis-Mahon, 2017), and increased education and survival do not necessarily imply greater health literacy (Jenkins et al., 2016). Older people, too, may struggle to understand and/or apply basic health information, even when health care professionals take into account aging (Federman, Sano, Wolf, Siu, & Halm, 2009; Kobayashi et al., 2015; Kobayashi, Wardle, Wold, & von Wagner, 2016; Serper et al., 2014).

Lower health literacy has been associated with greater use of health care services and higher case costs (Bailey et al., 2015; Haun et al., 2015). In addition, people with lower health literacy are less likely to use health information technologies that could result in better health outcomes and/or mitigate the effects of low health literacy (Mackert, Mabry-Flynn, Champlin, Donovan, & Pounders, 2016). Making content easier to read and comprehend, as described later in this chapter, can help to reduce the health inequity that results from low health literacy.

Although there are many things to consider when developing consumer health information, three ideas are particularly important: Know and write for your audience, base your content on appropriate sources, and create scannable content.

Know Your Audience, and Write for Them

Write with what your audience knows, wants, and needs in mind. Users have come to your content seeking insight into or resolution of their health concerns. They expect your content to perform a service, addressing their needs rather than your goals. Sharing what you want to tell users should never take priority over giving them what they have come to find.

Most frequently, you will write for a specific audience, such as people who must choose a treatment for a medical condition or review the latest treatment guidelines before prescribing a medication. When this is the case, you will already know some-

thing about your audience and can match the reading level and degree of detail to their needs. Write with the culture, health beliefs, and general health literacy of the target audience top of mind to better meet your audience's needs.

Health content for the general public, however, needs to be written so that all users can apply the information to their situation. In this case, you will want to avoid elements that are unfamiliar or may alienate users. For example, if you are writing about cleaning the genitals before engaging in sex, content that refers to use of a bidet would exclude users who do not know what a bidet is or lack access to one. Content that conveys simply the importance of washing with clean running water would be meaningful to more users.

If your content is broadly available, such as through a Web site that is not protected by a password, it may be difficult to determine who accesses your content. Basic Web analytics data, such as the URL where users were before they came to your content, may give you some sense of who uses your content. From that information, you may be able to infer user characteristics, such as level of education, which you can use to tailor content to your users.

However, a pressing personal or family health need may motivate users to work their way through more complex information than they are comfortable with. Clear writing, thoughtfully filled out with informational illustrations and well-chosen references, can help less literate users bridge the gap (Fig. 14.1). Ultimately, that is your goal.

If people outside your organization or country are likely to access your content, review your first draft with an eye toward making it understandable by all your users. Some people may access your content through a translation tool that lacks the ability to interpret idioms or explain references specific to your culture. Looking for and removing cultural bias will improve your content for everyone.

Base Your Content on Current, Respected Sources, and Update Your Content Regularly

Above all, users expect your content to be accurate, current, and complete. Outdated information is not only unhelpful but also may imperil users' health or the health of patients for whom they care. Users' ability to evaluate the quality of health information varies (Diviani, van den Putte, Giani, & van Weert, 2015), so it is particularly important that you set and consistently achieve high standards for your content.

Include complete references for all the sources on which your content is based. A complete reference list (Fig. 14.2) gives users the opportunity to read more about points that interest them. A number of personal characteristics (e.g., education, socioeconomic status, and age) influence users' perception of what makes information trustworthy, and thus providing a list of references helps them to evaluate the trustworthiness of your content (Brady, Segar, & Sanders, 2016; Kwon, Kye, Park, Oh, & Park, 2015; Ye, 2011). Citing the sources of your information also promotes transparency, helping users to build trust in your organization and your content.

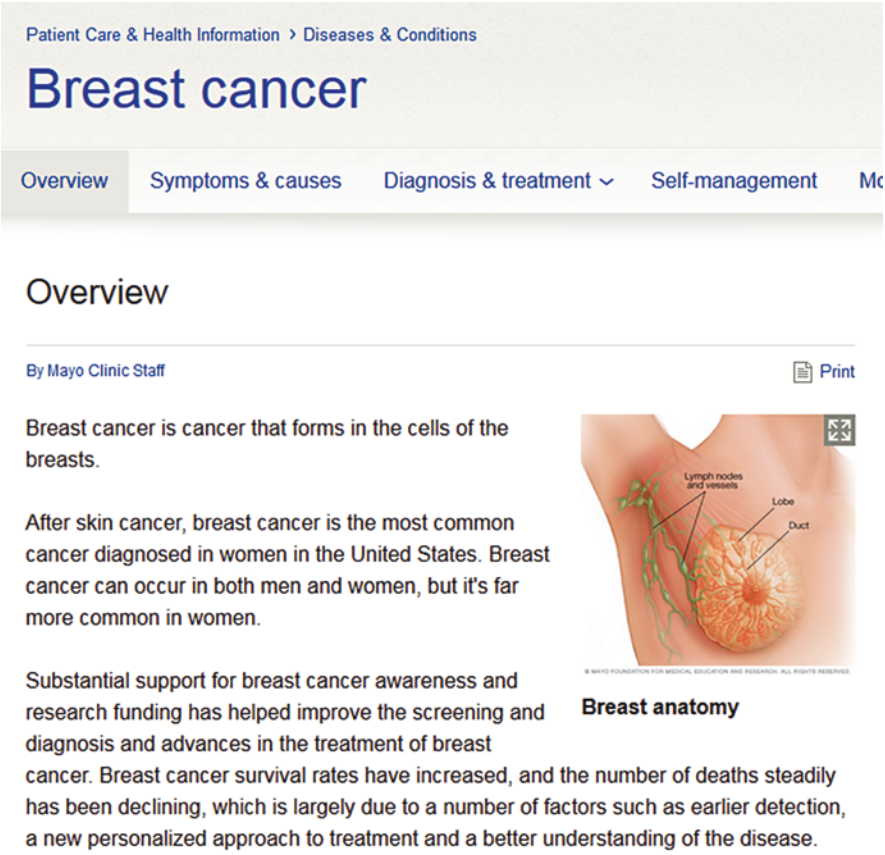

Fig. 14.1 Presenting clear, concise text with thoughtfully selected illustrations helps users with limited literacy skills

When there is no professional consensus among medical professionals about the topic of your content, describe the most commonly held perspectives and identify less widely accepted views. Noting theories that have yet to be supported by clinical research helps users put into context information they may have seen in the news and social media or heard from friends.

If resource limitations force you to choose between regularly updating your content and creating new content, focus your efforts on updating what you have. Inaccuracy becomes apparent relatively quickly—nearly overnight for topics that are the subject of much research (e.g., breast cancer) or are controversial (e.g., strength training for children)—and drives users to seek information elsewhere.

Avoid unsubstantiated generalizations. There is no way to determine the knowledge level of your users when creating content, and some people do not know what they do not know. You can help them fill in the gaps in their knowledge base by documenting your sources, as well as by including a list of more general references they can consult.

References Share on: Facebook Twitter Print Aug. 10, 2017

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Fig. 14.2 Including a complete list of references cited in content helps users locate sources they want to explore in greater depth

Write to Make Your Content *Usable* Rather Than *Readable*

Users scan, rather than read, online content (Nielsen & Morkes, 1997). Rather than reading every word on a page, users gauge the relevance of content by scanning titles, subheadings, and the beginnings of paragraphs. This behavior has several implications for content creators:

- *Short paragraphs*. Keep paragraphs short—even just a sentence or two, much tighter than in books and magazines—to facilitate a rapid scan. Use of short paragraphs also improves content readability on mobile devices, which may require more scrolling when text blocks are long.
- *Bullet lists.* Using lists of three to five highlighted bullets with brief commentary improves the scanability of items that require minimal explanation, such as lists of symptoms or medications. When bullet lists are an appropriate format for presenting information, but the number of items to include is long, covering the items in multiple bullet lists with transitions can help (Fig. 14.3).
- *Tight, clear headings and subheadings*. Titles, headings, and subheadings create a visual outline that helps the user determine whether the page addresses his/her concern.
- *Use illustrations wisely*. Select charts, infographics, and illustrations with care, and be sure they add to, rather than repeat, the textual content. Users do not want to be bothered with repetitious material, even when presented in different forms.

Some additional considerations to facilitate content usability include:

- *Use an outline*. Develop and follow an outline for each page of content. Before writing, define the scope of the page and incorporate that into the structure of the page (e.g., with a short introduction, navigation cues that illustrate what is included, or other device) so that users can quickly determine if the content is what they are seeking.
- *List the benefits of the content early*. Tell users what you will do to address their goal early in the content through text, headings and subheadings, and page navigation.
- *Highlight important connections*. Tell users why a piece of information or point is important. Nonexpert users may miss the idea if your content does not point out the relevance of your points.
- *Write in the active voice, speaking directly to users*. The use of second person voice is uncommon in academic and professional writing but brings a degree of warmth that users appreciate. Using active verbs helps you write more concisely and avoid unnecessary words that slow down users.
- *Use jargon with care*. When using technical terms that are likely to be unfamiliar to users, define terms such that users can visualize the concept. This approach allows users to learn about the topic of interest while building the vocabulary they will need to grasp more technical information.
- *Use correct grammar and consistent style*. Users can follow your content more easily when it is written in standard English and follows an established style such

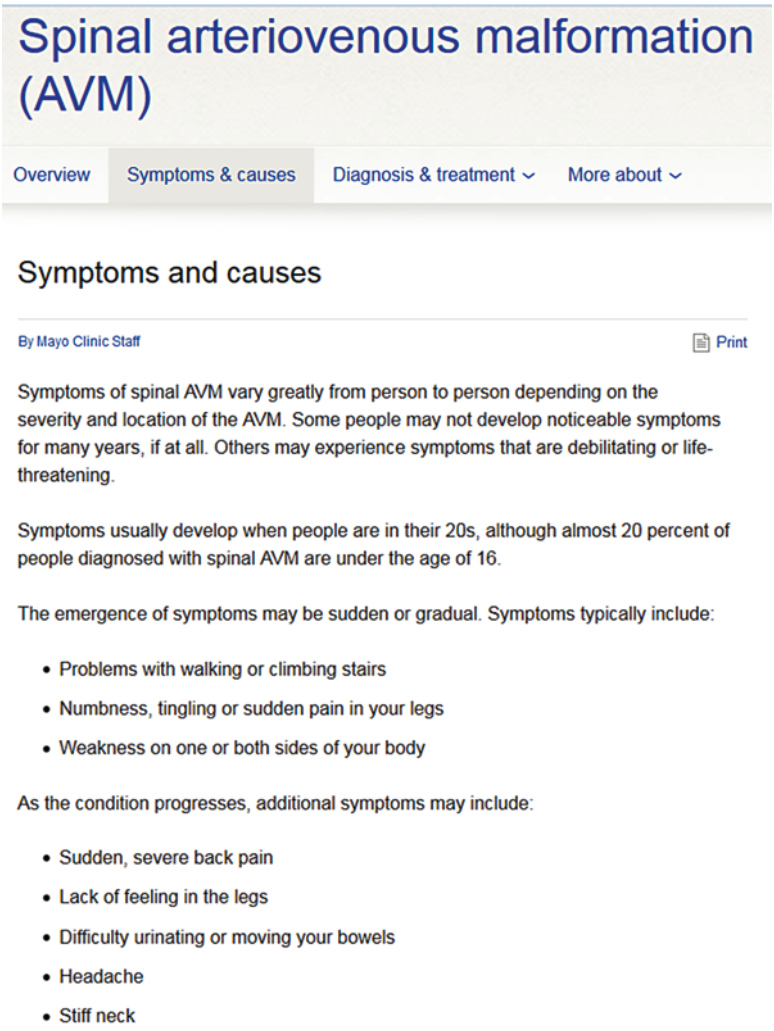

Fig. 14.3 Use short bullet lists to make scanning of content easier for users

as the Associated Press or Chicago style. In addition, Internet translation tools yield more accurate results when text is grammatically correct.

- *Write in a neutral, informative tone*. Whatever tone you adopt, stick with it throughout the piece of content and the site as a whole. Shifts in tone are jarring to users and may leave them with the impression that something is missing in the content. Avoid sarcasm and humor in your writing. Jokes that amuse you may offend others, particularly to those accessing your content in an unfamiliar language.
- *Interpret readability indices thoughtfully*. Readability indices assess the word and sentence complexity of a piece of text and assign a level of education, e.g.,

sixth-grade reading level, needed to comprehend the text. Readability indices can help you assess the degree of difficulty of content but do not tell you whether users will find your content readable and useful. Users may already know something about the topic and desire more detailed or technical information that exceeds their general reading level. Or, a pressing personal or family health need may motivate users to work their way through information written at a higher reading level than they prefer. When content must convey complex concepts, evaluate your content for clarity and use definitions to help users work through it.

Summary

Creation of high-quality health information results from thoughtful content planning and consistent application of style and grammar principles. Focusing on what users seek to learn from the content, rather than on what the content creator wishes to share, lays a foundation for a successful user experience. Delivering what is promised in a concise, scannable fashion allows users to efficiently complete their information-seeking tasks. Clearly documenting the sources on which content is based helps users determine whether they can trust the information and locate references for additional review. Attention to content purpose, clarity, and structure ensures that users have a positive experience and return again when they need further information.

Additional Resources

The following Web sites and reports provide further support for writing for the Web and reducing the impact of low health literacy.

Centers for Medicare & Medicaid Services. Toolkit for Making Written Material Clear and Effective.

https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/index.html?redirect=/WrittenMaterialsToolkit/

This 11-part toolkit shows how to take a user-centered approach, use writing and graphic design guidelines, and collect and apply user feedback.

DeWalt, D. A., Callahan, L. F., Hawk, V. H., Broucksou, K. A., Hink, A., Rudd, R., & Brach. C. (2010). Health literacy universal precautions toolkit. AHRQ Pub. No. 10-0046-ef. Rockville, MD: Agency for Healthcare Research and Quality.

https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf

This package provides the tools for improving written and spoken communications, quality improvement efforts, and process management when health literacy may be a concern.

National Academies of Sciences, Engineering, and Medicine. (2015). Health literacy and consumer-facing technology: Workshop summary. Washington, DC: The National Academies Press.

https://www.nap.edu/catalog/21781/health-literacy-and-consumer-facing-technology-workshop-summary

This workshop summary describes the challenges inherent in presenting health information to consumers, including the relationship of technology to health literacy and disparities, and design strategies for addressing these challenges.

The National Academies of Sciences, Engineering, and Medicine. (2004). Health literacy: a prescription to end confusion. Washington, DC: The National Academies Press.

https://www.nap.edu/catalog/10883/health-literacy-a-prescription-to-end-confusion

This book provides an introduction to the extent and challenge of health literacy and describes how it intersects with culture, society, health systems, and the educational system.

The National Academies of Sciences, Engineering, and Medicine. (2015). Health literacy: Past, present, and future: Workshop summary. Washington, DC: The National Academies Press.

https://www.nap.edu/catalog/21714/health-literacy-past-present-and-future-workshop-summary

This workshop summary describes the status of health literacy research in the USA and identifies future challenges and opportunities.

U.S. National Library of Medicine. (2017). Health literacy Web page https://nnlm.gov/initiatives/topics/health-literacy

This Web page explains the role librarians play in increasing health literacy and provides links to health literacy online resources.

U. S. National Library of Medicine. (2017). MEDLINE/PubMed search and health literacy information resources.

https://www.nlm.nih.gov/services/queries/health_literacy.html

This page shows how to search for publications on health literacy using MEDLINE and PubMed and includes links to numerous Web sites offering relevant publications.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). Health Literacy Online: A guide to writing and designing easy-to-use health Web sites.

http://health.gov/healthliteracyonline/2010/

This guide covers the assessment of user audience, writing actionable content, organizing and displaying content for usability, use of interactive elements, and Web site evaluation and improvement.

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Part IV
Policy and Regulatory Issues

Chapter 15
Leveraging Consumer Health IT to Incentivize Engagement and Shared Accountability in Value-Based Purchasing

Erin Holve

Purchasers' Role and Tools to Promote Value-Based Purchasing

Health care payers (self-insured employers, insurance companies, state Medicaid agencies, etc.) are increasingly playing a role as thoughtful *purchasers* of health care. Health care purchasers have a substantial role to play in achieving the "triple aim" of healthcare—better care, smarter spending, and healthier people (Centers for Medicare and Medicaid Services, 2016a, 2016b, 2016c). As defined by the Agency for Healthcare Research and Quality, "Purchasers" are public and private sector entities that subsidize, arrange and contract for—and in many cases bear the risk for—the cost of health care services received by a group of beneficiaries (AHRQ, 2002). This new approach is often referred to as value-based purchasing (VBP), a model in which the focus is on paying for value rather than volume of services.

Here, it should be clarified that the concept of value-based purchasing entails strategies to hold providers accountable for *both* cost and quality of care:

> Value-based purchasing brings together information on the quality of health care, including patient outcomes and health status, with data on the dollar outlays going towards health. It focuses on managing health care utilization to reduce inappropriate or unnecessary care and to identify and reward the best-performing providers. This strategy can be contrasted with more limited efforts to negotiate price discounts, which reduce costs but do little to ensure that quality of care is improved." (Rybowski & Eichler, 1997)

Most often, VBP models operate by enacting provider contracts that incentivize health care providers to achieve a set of targeted activities (e.g., ensure children receive all required immunizations) or health outcomes (e.g., reduce obesity rates). These health outcomes are usually assessed with respect to validated quality

E. Holve (✉)
Department of Health Care Finance, Government of the District of Columbia, Washington, DC, USA

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measures, which require uniform data collection and may require sophisticated calculations to adjust risk for patient acuity. These provider contracts may also be structured to provide bonuses for decreasing low-value care, such as the percentage of low-acuity visits to the emergency room, a goal intended to encourage provider and patient communication and care coordination.

As illustrated by the example above, VBP models necessitate robust health IT (Adler-Milstein, Embi, Middleton, Sarkar, & Smith, 2017). Successful efforts to implement VBP methodologies—from pay for performance to global budgets—entail a coevolution of technology, changes in practice patterns and workflow, and quality measurement strategies designed to promote improvement over time (see "Purchasers' Role and Tools to Promote Value-Based Purchasing"). Ideally, this approach to health system redesign will also demonstrate a variety of ways in which VBP can incorporate consumer health IT to improve health outcomes (Fig. 15.1).

Case Study: The US' Clarion Call to Improve Quality

In the early 2000s, poor quality care, including medical errors and suboptimal health outcomes, led to a clarion call for investment in infrastructure to shift the paradigm from paying for volume of services to value of services (McGinnis et al., 2002; IOM, 2000). Purchasers' role in leading this transformation has been viewed as a critical component of delivery system reform due to the substantial role purchasers play in deciding which plans and services to select. As of 2015, public and private healthcare purchasers, including employers and public insurance providers purchase insurance on behalf of 82% non-elderly Americans (Kaiser Family Foundation, 2016).

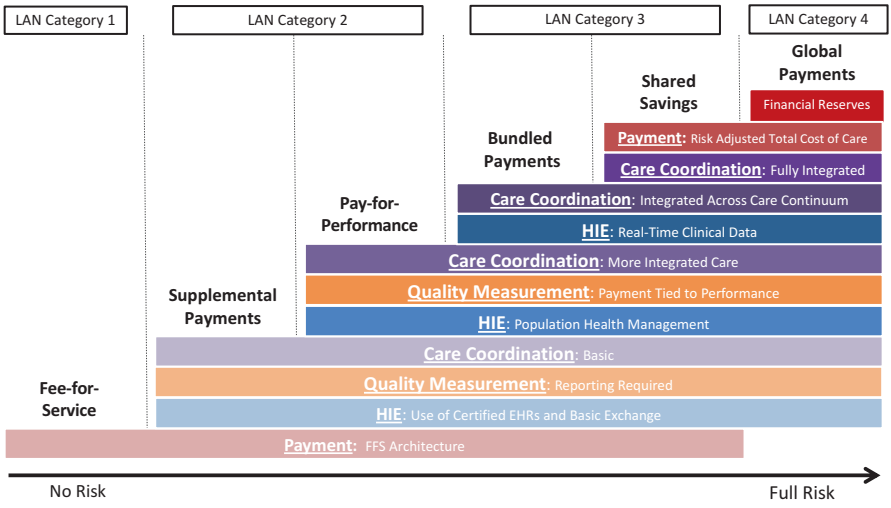

Fig. 15.1 Steps towards Managing Population Health and Risk: A Sophisticated Integration of Health IT, Changes in Practice, and Quality Measurement. Source: Author

Due to the extensive reach of employer-based coverage, combined with public coverage through state Medicaid programs and Medicare, the USA provides an effective example of the roles purchasers can play to promote VBP to measure, monitor, and improve the quality of care. Arguably, the US' ability to bend the "cost curve" for the US health spending is highly dependent on effectively deploying VBP strategies, which in turn will depend on the extent to which consumers and providers are given useful tools to guide practice change. For this reason, the majority of examples of VBP strategies discussed in this chapter are based in the USA.

As shown in Fig. 15.2, there are multiple goals of VBP. Over the short or intermediate-term, purchasers aim to promote opportunities for consumers to elect high-quality providers and services, choose appropriate utilization of services (and decrease low-value care), increase healthy behaviors including diet and exercise, and see a reduction in medical errors. Over the longer term, goals articulated by purchasers with respect to VBP strategies include increased health status and consumer satisfaction; decreased cost; and increased competitiveness for workers due to employee's selecting benefit packages that provide higher-quality services.

All of these VBP efforts utilize strategies designed to influence the decisions or behavior of individual consumers (i.e., employees, beneficiaries, and patients), and/or health care entities, usually providers and/or plans. Ideally, VBP strategies integrate efforts to support change at *both* the consumer and provider levels.

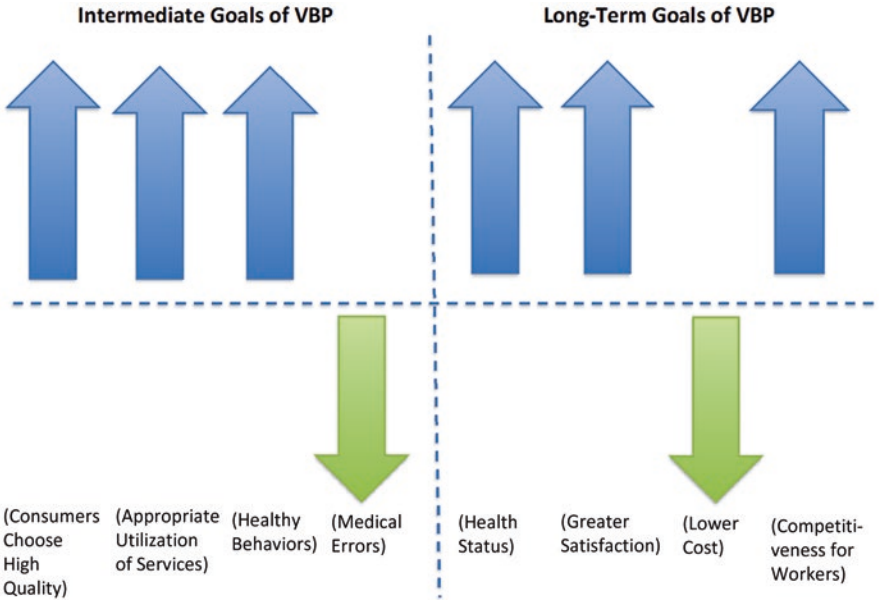

Fig. 15.2 Understanding the Intermediate and Long-Term Goals of Value-Based Purchasing* Can Contribute to the Design of Effective Health IT. Source: Adapted by author from AHRQ Issue Brief, Publication #02-0029, "Evaluating the Impact of Value Based Purchasing – A Guide for Purchasers"

Health IT, the Foundation of Value-Based Purchasing

The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009, provided financial incentives and technical support for providers to implement and use electronic health records (EHRs). This legislation conceptualized the notion of "meaningful use," that is, collection and application of electronic health data to improve health care practice and outcomes.

Improving the types of information available to providers and consumers reduces "information asymmetry," in which information among parties is unequal and therefore power dynamics are unbalanced. One recurring example of information asymmetry in healthcare is that information on an individuals' care is not always readily available to all involved parties. Clinicians often have more information on a clinical diagnosis than the patient, which can preclude the patient from taking a more active role in his/her care. Providers may have a limited view into an individual's health status or life circumstances if they are not part of a patient's regular care team.

Consider care provided to a patient experiencing an acute episode of care such as an asthma attack. To the extent the asthma attack is precipitated by environmental factors, or a lack of access to needed medications, a treating clinician may be at a disadvantage to provide the best care or treat the problem in a way that will prevent subsequent acute episodes. Health IT can address this asymmetry by providing the patient's history of care, medications, and history of medication refills, as well as information on how to reach the patient's primary care provider or care coordinator. Such health IT tools can ensure that health information is available to both providers and consumers at the right place and time in order to improve care and maximize healthy outcomes. This type of approach can also link together providers and patients to create virtual care teams and improve transitions of care. This is sometimes referred to as providing "actionable information" to providers and consumers.

Many VBP programs are structured to explicitly reward providers for addressing the root cause of acute health problems and seek solutions that promote health. Pay for performance programs that incentivize a reduction in hospital readmissions within 30 days is one example of this type of model.

However, information alone is not sufficient to change provider or consumer behavior. Information must be used in new ways to highlight opportunities to reduce waste and improve care, and to facilitate coordination care for complex medical conditions. Doing so will necessitate a change in workflows in the clinic, which will undoubtedly disrupt patterns of the current medical practice. Incentivizing a significant change in practice patterns and workflow requires that strong incentives are part of new purchasing models.

Health IT is foundational to VBP because provider and consumer-facing technology creates a capability to set goals and measure improvement against set benchmarks. Changes in the culture of healthcare delivery are more likely to be sustained if stakeholders have a full understanding of the expectations and outcomes against which performance will be measured (e.g., quality measures).

As discussed in the following sections, there are new opportunities for consumers to be actively engaged in the design, implementation, and ongoing evaluation of

VBP. It is now possible to ensure that VBP programs are responsive to consumer needs. Some of these innovations are based on health reforms in the Affordable Care Act, some on opportunities in consumer informatics, and some due to significant investments in developing structured approaches to consumer and patient engagement in disability rights and services, health care, and health research.

Purchasers' efforts to engage consumers in the design and deployment of health IT for VBP can borrow heavily from these cross-sectoral efforts since purchasing methodologies strive to support evidence-based medicine and best-in-class care. This research gives purchasers the confidence in their ability to set sustainable rates and payment incentives. Consumer engagement, health IT, and VBP models are creating new opportunities to measure and improve how care is organized, financed, and delivered.

Making the Most of Health IT to Engage Providers and Consumers

A key principle of delivery system transformation is the need for payers and purchasers to balance appropriate incentives and accountability while supporting patient-centered care and consumer engagement. While the theory of consumer-facing strategies for delivery system transformation is laudable, in practice, most consumers do not understand the major changes underway in the health care system. Furthermore, consumers are not well prepared to navigate this new terrain, either in terms of understanding the goals of VBP or their personal role. All are areas in which healthcare consumers can be more actively engaged in care, as well as the design of future VBP programs.

Implementation of diverse VBP programs has demonstrated the value of health IT to reduce information asymmetry, and engage providers as well as consumers in strategies to promote health (Manary, Staelin, Kosel, Schulman, & Glickman, 2014). Yet, health care purchasers have significant improvement to make in order to integrate consumer perspectives into the design of VBP. This section explores two approaches to engage consumers and providers in VBP: applying the so-called *patient-centeredness* and *design thinking* in principle and practice; and creating robust mechanisms for consumer feedback as value-based purchasing models evolve.

Person-Centered Care

As purchasers consider approaches to promote overall health and well-being, it is useful to embrace person-centered care as an underlying principle of VBP. "Person-centered care" and "patient-centered care" will be used synonymously in this discussion about ways to engage health care consumers, be they patients, community-members seeking assistance with health or social services, or caregivers.

The term "patient-centered care" originated more than a quarter century ago, and was identified as one of the six pillars of high-quality healthcare by the National

Academy of Medicine (formerly the Institute of Medicine) in its landmark report, "Crossing the Quality Chasm." (IOM, 2000) Patient-centered care is a philosophy that sees patients as equal partners in care with the goal of ensuring that care decisions are appropriate to meet individual needs, values, and preferences.

Patient-centered care focuses on compassion, dignity, and respect, emphasizing independence and decisional autonomy (The Health Foundation, 2014). Consumer-reported measures of patient-centered care and patient experience (including satisfaction ratings) are increasingly being reported alongside quality measures and scorecards. There is strong evidence that patient-centeredness is correlated with higher-quality care as well as improved outcomes (McMillan et al., 2013).

Person-centered thinking is a related concept used primarily in the social service sector. Person-centered thinking supports positive control and self-direction. The goal is to promote the greater likelihood that service plans will be used and acted on, and will be updated on an ongoing basis; and that the client or consumer's ability to lead a fulfilling, independent life is maximized (District of Columbia Department of Disability Services, n.d.). Due to the philosophical similarities between the two concepts, this discussion will not address the nuances of the person-centered thinking separate from patient-centered care. Nonetheless, it is important to understand both concepts and find ways to bring healthcare and social services together to design IT strategies that promote health.

It is important for leaders to review systems and services and take time to assess the degree to which patient-centered care is embedded in current programs. This can be done with any number of approaches to measuring the person-centeredness. For example, a 2014 systematic review of the literature by the Health Foundation in the UK cites numerous resources—and more than 150 internationally recognized measures (The Health Foundation, 2014). These measures are available to assist programs and organizations in assessing their orientation to patient-centered care.

Overall, initial assessment of the patient-centeredness of existing programs is a foundational step to design VBP programs. Choosing to incorporate program designs and Health IT tools that are patient-centered can significantly enhance the value of healthcare programs aimed at improving outcomes. While organizations identify a deficit in patient-centered care, there are trainings for organizations or individuals to enhance patient-centeredness.

Design Thinking

"Design thinking" (and the corollary concept of user-centered design) is increasingly invoked as an approach to build person-centered technology. Design thinking is grounded in ethnography, by observing people in their environment, and developing solutions that improve or enhance the way they live their lives.

As a simple example, a design thinking approach to presenting information on an individual's current health status (e.g., weight and blood pressure) could involve a conversation about individual health goals, followed by observation of a recipient

reviewing a mockup of the information. Based on feedback from these sessions to identify aspects that may be confusing or cryptic, information can be redesigned and presented in a way that the consumer can better understand, such as simplified language, or visuals.

With respect to designing health IT to support programs and a system of care that promote individuals' health, patient-centered care and design thinking are complementary concepts for healthcare leaders. Both should be assessed and addressed in the early stages of creating VBP programs.

Engaging Consumers in the Design of Health IT and VBP

Involving beneficiaries and patients in the design and implementation of health IT is another strategy to ensure that the technological tools that support VBP programs are responsive to consumers' needs.

In recent years, extensive work has been done in the context of patient-centered outcomes research to implement human-centered design principles in "learning health systems" (Foraker et al., 2015; Hartzler, Chaudhuri, Fey, Flum, & Lavallee, 2015; Payne, 2013; Revere, Dixon, Hills, Williams, & Grannis, 2014). This work is a relatively early proof of concept that consumers can be actively engaged in technology development for complex health programs, with broader implications for policy. Many of these efforts have generated methodologies for engaging consumers in software development and borrow from the agile approach to software development.

Figure 15.3 illustrates one framework for conceptualizing integrated design of VBP and Health IT, highlighting specific steps of the development process that can integrate feedback from consumers effectively.

A recent example illustrates the value of engaging end-users, particularly consumers, in the design of health IT tools deployed to motivate behavior change and improve quality. Hartzler and colleagues at the University of Washington provide a step-by-step process that they applied with clinical end-users to assess information needs and design a dashboard for Washington State's Surgical Care and Outcomes Assessment Program (SCOAP) spinal care registry (Hartzler et al., 2015).

The authors used a three-step human-centered design process to gather feedback on end-user preferences for the tool in which they sought to:

Understand the context of Health IT uses, including stakeholder interviews to provide the context in which the dashboard would be used to facilitate a conversation between patient and provider;

Build consensus through an iterative process of understanding user needs, determining design priorities, and sharing design prototypes to, and finalizing prototypes; and.

Establish design specifications for PRO Dashboard implementation including personalizing design prototypes.

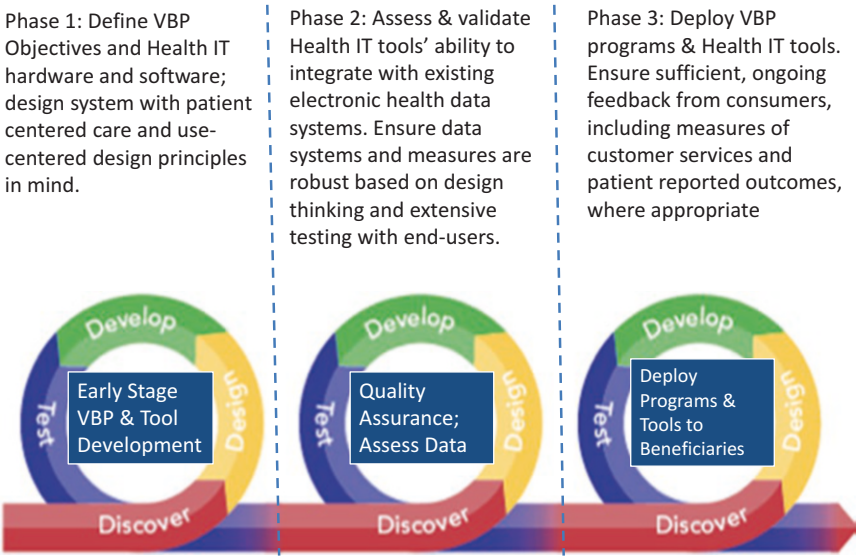

Fig. 15.3 An Agile IT Development Process Can be Applied to Engage Consumers in Designing Value-Based Purchasing Programs. Source: Author

This process and method is highly generalizable to the development of robust Health IT tools used to support VBP models. While Hartzler and colleagues did not explicitly employ this process with consumers for the Spine SCOAP project, their human-centered design methodology is highly transferrable to a consumer-facing strategy.

Patient Portals and Feedback Loops: Putting Individuals in Charge of their Own Health Information

Given the myriad applications for health IT in the care delivery context, the challenge for payers and purchasers is to identify which technologies truly put individuals in charge of their own information and build these into VBP programs. A first step may be to educate consumers on the paradigm shift in progress, as many may be unfamiliar with the notion and importance of moving from a volume-driven system to a value-driven one.

Beyond patient education, purchasers can progress towards developing consumer health IT and provider-mediated systems that put consumers at the center of their care, including system capabilities that allow patients to monitor and measure care and health outcomes. Prevalent examples include patient portals and the use of the EHR to collect patient feedback from patient-reported outcomes (PROSs), which can be used to monitor individual outcomes and guide a course of care (Snyder & Wu, 2017), as well as support quality measurement and reporting.

Price transparency tools are another technological approach to reduce information asymmetry. While these are promising strategies, the implementation of these approaches remains highly varied across practice.

Patient Portals

Some notable successes have been achieved within specific programs implementing ePHRs or "electronic personal health records" and patient portals. There is growing evidence that access and use of portals for visit summaries, lab testing, and facilitating email communication with providers may result in higher patient satisfaction and improved outcomes (Lyles et al., 2016).

The availability of ePHRs to complement electronic health records is a relatively recent phenomenon, owing to the development of ePHRs by Microsoft and Google, combined with support from large insurers such as Blue Cross/Blue Shield. The current drivers of ePHRs and patient portals are requirements of CMS' meaningful use program.

Although the regulatory requirements are subject to change, the capabilities and concepts entailed in meaningful use deserve review, since they directly support patient-centered care:

Clinical summaries provided to the patient after each visit,
Secure messaging (SM) between patient and provider,
The ability to view, download, and transmit personal health record data,
Patient-specific education,
Patient reminders for preventative services, and.
Medication reconciliation (Irizarry, DeVito Dabbs, & Curran, 2015).

These types of health IT system features provide core infrastructure to support VBP programs. A patient who can engage in secure messaging, view personal health data, and receive preventive care reminders is apt to be more engaged in wiser health-care decision-making, including individual purchasing decisions.

From purchasers' perspectives, engaging consumers to attain their feedback on care and care needs has potential to drive a virtuous cycle of direct consumer measurement and evaluation, which then informs the design of services that promote health. Patient portals are one way to ensure ongoing ability to exchange of information between consumers—including patients and caregivers—and providers.

However, a 2015 literature review of 120 articles summarizes a mixed experience with patient portals' results in terms of the ability to promote patient engagement and ideal features of patient centeredness such as self-efficacy (Irizarry et al., 2015). Sorondo and colleagues report similar results based on the use of a patient portal to collect wellness information at Eastern Maine Medical Center from 2013 to 2016 (Sorondo et al., 2016), which the authors attribute, in part, to system-level challenges.

The key impediments to successful and widespread implementation of patient portals identified by Sorondo and colleagues include: (1) adoption by providers, (2) the ease of use of the technology, and (3) a lack of full integration with clinical EHR

systems. VBP programs should be mindful of these challenges if consumer participation via patient portals is a core component of a consumer-facing strategy.

Patient-Reported Outcomes

Patient-reported outcomes (PROs) are another useful method of promoting patient engagement and feedback. PROs can put the patients' voice at the center of care, since they are designed to collect patients' self-reports of symptoms and experiences using structured, scientifically validated survey instruments. PROs enable providers/health systems to use a variety of forms of health IT to gather meaningful feedback from patients and consumers. PROs have flexibility to be reported in real time, yet can be collected separately from a healthcare encounter.

An increasing range of options for collecting PROs using health IT are currently available—via cell phone (Adler et al., 2016), interactive voice response (IVR), to data collection via iPad (Wilcox, Gallagher, & Bakken, 2013), patient portals, and kiosks. PROs can also support quality measurement of progress towards a clinical outcome (Centers for Medicare and Medicaid Services, 2016a, 2016b, 2016c; Chenok, Teleki, SooHoo, Huddleston, & Bozic, 2015; Lavallee et al., 2016; National Quality Forum, 2013).

Use of PROs is particularly promising for self-reports of symptoms in which medical diagnostics and imaging may be less predictive of symptom reduction. Mental health status, and pain and functioning (e.g., for knee and hip replacement) are two examples of conditions for which self-reported symptoms are generally valid measures of burden of illness (Mitchell, Yadegarfar, Gill, & Stubbs, 2016; Rolfson et al., 2016).

As discussed in PCORI's new Users' Guide for Integrating Patient-Reported Outcomes in Electronic Health Records (Snyder & Wu, 2017), PRO data is increasingly used within EHRs to provide ongoing feedback regarding patients' direct reports of symptoms, functioning, and health-related quality of life. As PRO measures are developed and validated for use by payers and purchasers, there is growing interest in using dynamic strategies via mobile technology to measure care quality and outcomes, rather than more general patient-generated health information or satisfaction data reported via survey.

Similarly, at the provider level, new technologies are being developed to integrate PROs from the EHR directly into measures reported to federal payers such as CMS, including the National Institutes of Health's PROMIS System (National Institutes of Health, 2017). Newer tools such as the Clinical Quality Measure Aligned Population Health Reporting Tool (CAliPHR) ease the burden of reporting for providers, thus making it practical for purchasers to require PROs as a component of value-based purchasing models (Chesapeake Regional Information System for Our Patients, n.d.).

PROs are also being used by organizations to predict the need for future resources. Bayliss and colleagues reported a novel implementation of the Brief Health Questionnaire used to predict resource needs for newly enrolled beneficiaries within

Kaiser Permanente Colorado (Bayliss et al., 2016). The authors demonstrated that the 10-item questionnaire, covering self-reported health status, functional limitations, medication use, presence of 0–4 chronic conditions, self-reported emergency department (ED) use during the prior year, and lack of prior insurance, was significantly predictive of high-cost care.

As sophistication using and implementing PROs in practice grows (e.g., within the EHR or other IT systems), purchasers may soon have patient-reported quality measures that can be used to differentiate important health outcomes. If this trend comes to pass, purchasers will likely require that an increasing number of quality measures included in VBP contracts are based on PROs. Such a strategy would ensure that the patient voice is reflected in the outcomes used by VBP programs to motivate behavior change among providers.

Interactive Tools to Promote Price Transparency

Finally, interactive tools to promote price transparency, budgeting, and service comparisons are becoming available to reduce information asymmetry with respect to cost and quality of services. Numerous websites now provide cost-comparison information on health plans, distinct services such as joint replacement, pregnancy care, or diagnostic imaging, and some provide detailed cost information to inform consumers about the quality of outcomes as well as out of pocket costs (Consumer Reports, 2016).

While this is a dynamic area with new market entrants seeking ways to provide information on prices to health care consumers, it is unclear how consumers are responding to such services. A 2016 *Consumer Reports'* review of 20 cost estimator tools (including five stand-alone services such as FAIR health) demonstrates that few consumers currently use these tools (Consumer Reports, 2016). This lesson has been underscored by the experience of companies such as Castlight Health, which has faced challenges meeting market expectations. Castlight provides employees with information about the price and quality of services offered by healthcare providers. Castlight was touted as an opportunity to revolutionize consumer understanding of health care prices and quality, as evidenced by a $2 billion valuation at its initial public offering in 2014 (Seeking Alpha, 2014). However, it remains to be seen whether the company—or other similar ventures—will achieve anticipated returns and substantially change consumer behavior.

Nonetheless, the expectation is that price transparency will improve as data sources mature. The presumption is that high-deductible health plans and other approaches to reducing moral hazard by requiring consumers to have more financial "skin in the game" will reduce inappropriate utilization and improve health outcomes. However, it does not seem that we have yet reached an appropriate balance between available information and incentives to use data on price and quality (Kliff, 2015). For VBP programs interested in integrating consumer-facing strategies, it will likely require time and attention to build price transparency tools into an effective and well-coordinated system of care.

Emerging Trends and Future Opportunities: Incorporating Life Circumstance into VBP through Consumer Health IT

Collection and use of social determinants of health data, or life circumstance data, has been identified as a promising next step for VBP (Spencer, Freda, McGinnis, & Gottleib, 2016). Socioeconomic and environmental aspects of individuals' lives, such as food availability, housing, safety, transportation, and family circumstances, as well as personal characteristics have bearing on an individual's ability to access health care and their ability to be healthy and stay healthy.

The National Academy of Medicine, among others, has suggested that 80% of factors contributing to health and wellness fall outside the realm of clinical influence (IOM, 2003). In response, health and social service sectors recognize a pressing need to incorporate life circumstance and a broader perspective on the whole person into care delivery. Incorporating these data across sectors is only possible with effective health information exchange (HIE).

Purchasers would do well to attend to life circumstance when designing tools that support their consumers' choices about healthcare consumption. For example, a consumer who lacks reliable transportation to a clinician's office may defer or delay necessary care, possibly ending up in an emergency room. This could be attenuated through virtual visits or telemedicine: thus, purchasers designing VBP approaches should consider the ways in which social determinants drive health care choices for their particular population. This is a particularly important consideration in rural areas and for vulnerable or disadvantaged populations.

Consumer-facing health IT is a likely path to collect and share information on life circumstances. Using a structured approach to data collection, consumer information can be collected to better assess health needs, promote effective referral patterns and transitions of care, and close the loop with respect to participation in health programs.

Yet, significant challenges impede collection and use of these data to promote behavior change among providers and health care consumers. Some stakeholders have sought to minimize barriers to collecting social determinants by proposing strategies to collect this data in a structured, unified way so that the information can be used in multi-sector collaborations.

As one example, the National Association of Community Health Centers has developed the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE), which many organizations are adopting as a standardized approach to screen for social determinants of health (National Association of Community Health Centers, 2016). Nonetheless, many organizations use unique measures they have developed to meet their client's service needs, and may be reluctant to discontinue current data collection that they perceive meets their needs.

The degree of variation in measures used by health and social programs has led to a patchwork of diffuse measures of related concepts such as housing insecurity, food insecurity, health literacy, access to transportation, stress, and so forth. In a recent meeting convened by the Department of Health Care Finance in the District of Columbia (DC's Medicaid program), stakeholders identified more than 50 tools to measure domains of social determinants. The underlying differences in approaches to measuring social factors that influence health makes it difficult for purchasers to

coalesce around common measures. Without common, accepted measures, it will be difficult for purchasers to benchmark quality or design VBP programs that reward providers for addressing life circumstances as part of the care process.

A related consideration is the need to design value-based measures that present a uniform set of goals. It is unclear as yet what level of health improvement can be expected based on interventions to address social determinants of health, such as permanent supportive housing, programs to provide supplemental nutrition, educational interventions, etc., and other relevant factors (Spencer et al., 2016). As a consequence, risk adjustment models, and rate setting methods that incorporate data on social determinants—both core components of a value-based purchasing program—are not widely available.

A number of ventures and publications suggest that focused attention to social determinants will bear fruit in the coming years. An influential series of publications from the National Academy of Medicine on "Vital Directions for Health and Health Care" includes recommendations related to purchasing strategies and health inequities, observing that, "Differential access to high-quality health care services can create health disparities. These inequities can be rectified by aligning reimbursement strategies to increase access, by expanding the array of services that are reimbursed, and by improving the quality and efficiency of services. Better links between health care and public health activities could increase the effects of health expenditures" (Adler et al., 2016).

In addition, a set of new grant programs sponsored by the Robert Wood Johnson Foundation Data Across Sectors for Health (DASH) programs, the US Office for the National Coordinator Community Health Peer Learning Program, and projects sponsored by the Patient-Centered Outcomes Research Institute, such as the PArTNER grant, seek to improve our understanding of how best to employ consumer-facing technology to collect and use data on life circumstance. Savvy purchasers could leverage the results of these efforts to understand the impact of feedback from consumers on nonclinical factors on health and wellness.

Summary/Conclusions: Paying for Technology–Enabled, Whole–Person Care

Transforming the health system to pay for value rather than volume of care entails complex interactions to implement new Health IT tools, change workflow and current practice patterns (Patterson et al., 2015), and integrate the voice of the patient/consumer. Purchasers and healthcare stakeholders will need to work together to monitor and address feedback from providers and consumers. The goal is see a coevolution of technology, changes in practice patterns and workflow, and quality measurement through continuous adjustment and improvement over time. As purchasers pursue this new model, it will be critical to routinely assess the extent to which VBP programs and their underlying technologies are patient-centered. Pursuing user-centered design principles to develop and test consumer-facing applications with patients and caregivers is equally important.

Finally, development and implementation of robust, validated approaches to measure and monitor consumer experience directly will be important to the entire health care enterprise. Such approaches will have the corollary benefit of promoting price transparency and minimizing information asymmetry for purchasers, providers, and patients alike. Patient portals, PROs, and quality measures that integrate patient feedback into the patient's electronic record are all promising strategies that leverage consumer health IT. Many of the approaches to integrate patient feedback into ongoing measurement and quality reporting via the EHR are still in their infancy, yet there is reason for optimism as delivery systems such as Kaiser Permanente, Intermountain Healthcare systematize this type of feedback (Snyder & Wu, 2017).

Well-designed payment models that successfully leverage health IT will enable a new perspective on consumer needs and experience. Purchasers stand to gain from these perspectives as they develop VBP programs that appropriately align incentives and approaches to meaningfully improve health care quality and outcomes. Integrating consumer health IT with VBP is a frontier with few successful exemplars to date, yet this is necessary work with a promising future. Ensuring that payment models support consumers to become more active participants in their care is a necessary component of these efforts. Together, consumer health IT and value-based purchasing are critical steps towards sustainably transforming the health system to achieve higher quality and better health outcomes.

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Chapter 16
Co-Creating a Community Roadmap for Interoperability

Susan C. Hull and Margo Edmunds

Introduction

After decades of focusing on the health care system as the main driver of health and health outcomes, more people across many sectors are recognizing the influences of social, economic, and environmental risk factors as predictors of health disparities at both individual and community levels. Given that local circumstances have the most direct influence on people's lives, the number of regional and community-based initiatives to promote health equity has been growing rapidly in the past few years, encouraged by the Affordable Care Act's emphasis on population health and consumer and community engagement and supported by federal, state, and local government initiatives as well as by philanthropic organizations such as the de Beaumont Foundation, Kellogg Foundation, Kresge Foundation, Robert Wood Johnson Foundation, and others.

This chapter begins with a description of the goals and effects of some of the early, foundational initiatives to promote community health, focusing on the WHO's Healthy Cities/Communities movement and Healthy People, led by the Office of Disease Prevention and Health Promotion at the US Department of Health and Human Services. We then describe the Community Health Information Network (CHIN) movement and assess the role of subsequent national guidance on interoperability in activating community organizations to develop performance measures and collect data on their success in meeting local health goals, with an emphasis on measuring affordability and social risk factors. Finally, we describe some of the most promising recent efforts to integrate work on social risk factors through multi-sector data sharing efforts at the local level.

S. C. Hull (✉)
Gartner, Inc. Stamford, CT, USA

M. Edmunds
AcademyHealth, Washington, DC, USA

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We recognize that most social, economic, environmental, and behavioral determinants of health and health status are influenced by actions and encounters that occur outside the traditional walls of institutional healthcare settings, including the home, neighborhood, schools, places of employment and recreation, retail, and other locations where people live, work, and play. Our goal is to familiarize readers with some of the key foundational influences and insights from community health work when technology adoption was at a much earlier stage of development.

Three Decades of Communities Impacting Health

Healthy Cities and Communities

The Healthy Cities and Communities movement of the 1990s generated a variety of multi-sector collaborations that shared responsibility for state and local health programs and provided foundations for the current initiatives in chronic disease prevention, health equity, community benefit, and social determinants of health.

Healthy community efforts in the United States (USA) were modeled after the World Health Organizations (WHO) adoption of The Healthy Cities movement in the late 1980s, when 11 European cities launched pilot projects. In just over 20 years, the number has grown to 1200 cities and 30 participating countries (Pittman, 2010). Diverse stakeholders include public and private healthcare and public health organizations, foundations, businesses, municipalities, and faith-based and civic organizations convened these healthy community efforts in the USA as multi-sectoral partnerships. Funded by private foundations and the government, their vision and actions focused on measurably improving health, well-being, and quality of life at the community level.

After the US Department of Health and Human Services (HHS) asked the National Civic League to help launch the US Healthy Communities Initiative (Norris & Pittman, 2000), Healthy Boston, California Healthy Cities, and the Collaborating Center at Indiana University paved the way for the nascent US movement. Common facilitators in these early efforts to appreciate the complex set of dynamics that influence individual, family, neighborhood, and community health included:

- Neutral convening.
- Voluntary agreements.
- Charismatic leadership.
- Transparency in decision-making.
- Asset mapping and systems thinking.

Hundreds of community partnerships, health care organizations, human services and public health agencies, and community-based organizations have adopted the Healthy Communities approach to community building, many forming and reforming

their initiatives over time, including up to today (National Civic Review, 2014). Healthy Communities participants collaborated to learn outcomes-based planning, to identify a common set of community health indicators, and to measure effectiveness of these contributions.

Healthy People 2000–2020

These community-based efforts were often aligned with the US Department of Health and Human Services, Healthy People 2000 program, launched by the Office of Disease Prevention and Health Promotion in the Office of the Secretary in September 1990. Healthy People began as a set of national health promotion and disease prevention objectives for improving the health of Americans by the end of the twentieth century and has continued now into a fourth decade. Twenty-first century Healthy People 2020 objectives include four overarching goals:

1. Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death;
2. Achieve health equity, eliminate disparities, and improve the health of all groups;
3. Create social and physical environments that promote good health for all; and.
4. Promote quality of life, healthy development, and healthy behaviors across all life stages.

While the objectives are national in scope, the original intention was that their achievement would be accomplished primarily through state and local community efforts. Refinements in the program have prioritized the focus of the objectives from 42 priority areas in 1990 to 22 priority areas for 2020. The program endures today as a framework for guiding communities and organizations to assess their needs and assets, set priorities, and collect local and state data.

For example, communities are encouraged to start local dialogue about the underlying causes of poor health or quality of life by digging deeper to get to the roots of issues they care about and are working to improve (see Table 16.1).

In summary, these decades of the healthy cities, communities, and people movements have focused on systems change, growing a different vision for how people live and work together, how community and health services are delivered, and how Improvement efforts, decision-making, and measurement of collective impact are most effective when spread throughout the community. These efforts have amplified the idea that the health of the individual is deeply influenced and shaped by the health of the community, and that individuals, families, and neighborhoods contribute to the health of the whole.

Table 16.1 Example of healthy people community tools

Dig Deeper: Getting at the roots of the issue social determinants of health
Start a dialogue about the underlying causes of poor health or quality of life in your community. *How do the 5 social determinants of health* discussed in Healthy People relate to your issue(s)?
1. How does the physical environment affect the health of your community (for example: water and air quality, availability of safe walking paths or sidewalks, housing standards)?
2. How does access to health services affect the health of your community?
3. How do biology and genetics affect the health issue you are trying to *address?*
4. How does the social environment affect the health of your community (for example: income level, education level, unemployment, language)?
5. How does individual behavior affect the health *issue you* are trying to address?
Are there interventions and/or strategies you can adopt to effect change at the root level, ultimately improving the health of your *community?*

Source: HealthyPeople.gov https://www.healthypeople.gov/2020/tools-and-resources/program-planning/Assess

Multi-Sector Health Data Exchange

One of the key challenges for multi-sector community health collaboration is the design and implementation of interoperable electronic information systems that follow patients and/or clients across a variety of health and social care settings within their communities. We are just beginning to learn what kind of information sharing practices, interoperability guidance, and distributed community infrastructure is needed to implement interventions that last long enough to create sustainable change. Systematic improvements in community health require an investment in infrastructure that supports robust data sharing but is more than "just" data sharing. Specifically, there needs to be an infrastructure that considers governance, as well as technical, methodological, process/workflow, and financing issues.

Early Efforts Share Data and Reports Across Institutions

Early on, these healthy community/city efforts recognized the challenges, yet need for health-related data sharing across community government, private-sector agencies, and health care settings. Some of these community experiments were at the forefront of the Community Health Information Network (CHIN) movement in the early to mid-1990s. CHIN provided technology-based services to maintain and improve optimal health for all residents of a community with promise to support a fully integrated longitudinal health record and a national network of mature CHINs.

Many of the early CHIN and health information exchange efforts, however, were disbanded for a variety of reasons, including minimal levels of electronic health technology adoption by clinical providers at the time, the perceived need for a centralized community-based data repository, perceived loss of control and lack of trust in the process, high costs, and lack of sustainable business models, including a

process for organizational change management, e.g., clinical workflow (Lorenzi, 2003; Vest & Gamm, 2010). In short, few had the requisite resources and leadership to meet the challenge of simultaneously building and demonstrating end-user value for these new assets, which we now know can take a long time to build and mature before they are actually useful.

These early efforts focused on sharing clinical health data and reports across institutions, for the benefits of providing limited data to payers, employers, researchers, providers, and other stakeholders (Vest & Gamm, 2010). Health data interoperability was a nascent concept at this time, addressing the fragmented nature of personal health information, its creation, stewardship, storage, and exchange across organizations.

Benefits in terms of savings were focused on the costs associated with moving data between providers and stakeholders to reduce redundancies and improve efficiencies, not on the potential applications for broader health improvement or making public community health level data also available to local organizations. Technology advances at the time were only beginning to anticipate a time when consumers would also be mediating health information exchange as personal citizens.

Data Sharing Expands to Create a Culture of Health Equity and Affordability

Many of the legacy community health efforts are now reframing their focus on accelerating change at a community level by building a culture of health, equity, affordability, and value. For example, The Network of Regional Health Improvement (NRHI), a national organization of regional healthcare improvement collaboratives (RHICs), and the Strategic Health Information Exchange Collaborative (SHIEC), the national trade association of HIEs, announced a formal partnership in October 2017. With a combined footprint covering almost 75% of the US population, and with operations in 44 states, including 30 RHICs and 50 HIEs, their intent is to broaden the reach and impact of both organizations by bringing claims, clinical, and social determinants of health data together faster, while learning from each other's areas of strength and experiences.

NRHI is also expanding its Getting to Affordability initiative, funded by Robert Wood Johnson Foundation, which is measuring and comparing variations in total cost of care (TCoC) in more than a dozen regions across the USA (Mitchell, 2017). By focusing on improving quality, efficiency, and communications among local systems of care, many of the "super utilizers" who have social, behavioral, and environmental issues will begin to have more support that reduces the number of repeat encounters with expensive services, such as the emergency room, and addresses other determinants of health.

Consumers Engage Within and Outside of Healthcare

Shifting emphasis from healthcare systems to communities has required multiple iterations in approaches in cross-sector health data sharing and IT infrastructure. Another major shift in thinking about consumer engagement came in the early 2000s, with the growing recognition of the central role consumers play in co-producing health and contributing to and being influenced by the health of their communities. In part, this was a reaction to the availability of new information with the launch of new consumer sites on the World Wide Web, but there were other forces as well, including an increase in media attention on the problem of medical errors (e.g., Leape, Woods, Hatlie, et al., 1998; Millenson, 2002).

These included national and professional society initiatives focusing on growing adoption, use and exchange of electronic and personal health records, as well as other efforts to provide a broader framework for consumer engagement. Taken together, these efforts foreshadowed new understandings about the need for health data interoperability and exchange with community members as network participants.

Consumer eHealth Defined

Nearly three decades ago, Kaplan and Brennan (2001) reported on the new field of consumer health informatics forming within the American Medical Informatics Association (AMIA) community, featured in 2000 Spring Congress track entitled "Consumer Informatics Supporting Patients as Co-Producers of Quality." Emergence of this specialty recognized previous decades of informatics development, which assumed the primacy of the patient–provider encounter creating health information, and applications development focused on the needs of providers or health care institutions. Data models and emerging definitions of interoperability were based on episodic patient encounters, with patient records organized around them, rather than around the life course of the individual patient.

The dominant care model of episode-based, provider-focused approaches expects consumers to integrate their own care, services, and information across changing health care delivery environments. Recommendations from the 2000 AMIA Congress focused on supporting patient–provider–information technology partnerships organized around the person involved; and advancing patient-centered systems and virtual, not physical structure for healthcare and health care information delivery.

> Consequently, medical and health informaticians need to build informatics tools that support the patient as a partner in health care and focus on the consumer, not the provider or institution. (Kaplan & Brennan, 2001, p. 312)

The Markle Foundation also laid significant groundwork recognizing consumers as Healthy Community network participants. Markle's convening of federal stakeholders, including the National Committee on Vital and Health Statistics

(NCVHS) and the American Health Information Community (AHIC), professional societies, consumer groups, health insurance plan associations, and bipartisan political leaders resulted in the landmark Common Framework for Networked Personal Health Information (2008). As stated in the Markle report, "Networked" Personal Health Records (PHRs) as Tools for Transformation (2008):

> The mere aggregation of the consumer's data, however, should not be an end in itself. The true test is whether the network makes it easier for ordinary people to coordinate and engage more actively in their own health and health care. We see a networked environment for PHRs as a foundation for Americans to improve the quality and safety of the care they receive, to communicate better with their doctors, to manage their own health, and to take care of loved ones (The Markle Foundation, 2008, p. 3).

Markle's work along with the Consumer Partnership for eHealth (managed by the National Partnership for Woman Families) and other thought leaders eventually helped to stimulate the formation of the Office of Consumer eHealth at the Office of the National Coordinator for Health IT (ONC) within HHS.

Consumer Engagement in Health IT

One of the first major efforts of the ONC Office of Consumer Health was the voluntary Consumer e-Health pledge program, later known as the Blue Button pledge. Blue Button eventually attracted over 500 organizations, including federal agencies, health care provider systems, health insurance plans, labs, retail pharmacies, and others committed to enabling consumer access to their online health data or to getting the word out to fuel more consumer awareness and demand for access to their digital health data. In 2013, ONC convened focus groups did consumer testing, and developed a set of public service announcement (PSA) videos and posters about Blue Button, securing commitments from influential organizations to distribute these materials in 2014 via an ongoing national Blue Button Campaign (Hull, 2014).

The ONC team (Ricciardi, Mostashari, Murphy, Daniel, & Siminerio, 2013) developed a National Action Plan to support consumer engagement via e-health with a strategy to increase access to health information, support the development of tools that enable people to take action with that information, and shift attitudes related to the traditional roles of patients and providers. Featured in a special issue of the journal of *Health Affairs* on consumer e-health, the Action Plan gained coverage by the national print news and media outlets.

Market proliferation of consumer-focused mobile health tools, patient portals, and pledge community commitment to spread and scale Blue Button (Hull, 2014) recognized early challenges in data sharing and exchange. Interoperability of health data as defined by the needs for the consumer gained new attention, as the practical implementation of these efforts highlighted many gaps in shareable comparable data for consumers and other data holders in the ecosystem.

In 2014, the ONC launched a formal vision through an Issue Brief: Using Health IT to Put the Person at the Center of Their Health and Care by 2020 (Daniels,

Deering, & Murray, 2014). While this effort clearly put the person at the center of care, it did not address the powerful reciprocal nature of individual's health to community health, health services delivered in and by community and social service agencies, and the potential role of the community to partner and catalyze and monitor this value shift.

Nationwide Roadmap for Interoperability and Learning Health System

In 2015, the ONC sought national feedback for achieving nationwide health data interoperability and enabling a broad scale learning health system by 2024. The Connecting Health and Care for the Nation Series, including *A Shared Nationwide Interoperability Roadmap version 1.0*, laid out multi-year calls to action and commitments to achieve high-quality care, lower costs, and contribute to a healthy population and engaged people.

While this effort was not framed in the context of data sharing for community-level exchange, it continued momentum with language to "put the person at the center" of care, and posited that interoperability was needed on many scales through multi-sector actions to improve the health for individuals, families, and communities. Time-based goals for achieving the 2024 objectives include:

- *2015–2017*: Send, receive, find, and use priority data domains to improve health care quality and outcomes.
- *2018–2020*: Expand data sources and users in the interoperable health IT ecosystem to improve health and lower costs.
- *2021–2024*: Achieve nationwide interoperability to enable a learning health system, with the person at the center of a system that can continuously improve care, public health, and science through real-time data access.

In defining who the Roadmap is for, a broad range of people and organizations traditionally involved in the delivery of clinical care (providers, individuals, and payers) and many outside the care delivery system who impact the health of individuals (schools, community-based social and human service organizations, and research community) were identified. Broad stakeholder groups were identified as those who will build the infrastructure needed for interoperability and for those who will use the infrastructure—and those best positioned to take on critical actions and/or will benefit from other actions to be taken are defined. Table 16.2 provides a graphic representation of defined stakeholders and their activities.

While the Roadmap expresses a broad view of "person at the center" health in the context of improving health for individuals, families, and community, there is not an explicit call to include healthy community partnerships as a Stakeholder Perspective. Related "Calls to Action and Commitments" are primarily focused on traditional healthcare settings. While stakeholders for the roadmap are members of

Table 16.2 Stakeholder perspectives included in the A Shared Nationwide Interoperabilty Roadmap, version 1.0

Figure 5: Stakeholder Perspectives

People who receive care or support the care of others
Individuals, consumers, patients, caregivers, family members serving in a non-professional role and professional organizations that represent these stakeholders' best interests

People and organizations that deliver care and services
Professional care providers who deliver care across the continuum, not limited to but including hospitals, ambulatory providers, pharmacies, laboratories, behavioral health including mental health and substance abuse services, home and community based services, nursing homes and professional organizations that represent these stakeholders' best interests

Organizations that pay for care
Private payers, employers and public payers that pay for programs like Medicare, Medicaid and Tricare

People and organizations that support the public good
Federal, state, tribal and local governments

People and organizations that generate new knowledge, whether research or quality improvement
Researchers, population health analytics and quality improvement knowledge curators and quality measure stewards

People and organizations that provide health IT capabilities
Technology developers for EHR and other health IT, including but not limited to health information exchange (HIE) technology, laboratory information systems, personal health records, pharmacy systems, mobile technology, medical device manufacturers and other technology that provides health IT capabilities and services

People and organizations that govern, certify and/or have oversight
Governing bodies and accreditation/certification bodies operating at local, regional, or national levels that provide a governance structure, contractual arrangements, rules of engagement, best practices, processes and/or assess compliance

People and organizations that develop and maintain standards
Standards development organizations (SDOs) and their communities of participants, such as technology developers, health systems, providers, government, associations, etc.

Source HIT.Gov: **https://www.healthit.gov/sites/default/files/nationwide-interoperability-roadmap-draft-version-1.0.pdf, Fig. 5, p. 22**

communities, the roadmap does not formally recognize community partnerships or collaboratives, or the vital role they share with other stakeholders, such as Public Good Stakeholders.

Guidance on Interoperability at the Community Level

Taking practical action steps to assess and improve health data interoperability at a community level is a novel construct, given the three decades of history highlighted in this chapter. What is still needed in terms of technical, social, and political infrastructure to support community health improvement? How will interoperability be defined from a community perspective?

Significant progress has been made in defining a holistic and interdependent view of health, recognizing the influences of social, economic, and environmental risk factors as predictors of health disparities for the individual, family, and community. Widespread adoption of health information and data exchange technologies, including novel mobile and personal health solutions, are surfacing new questions about interoperability, not only for data sharing across institutions, but also for the person at the center.

Concerns about consumers' access to health information, and their ability to direct and mediate health data exchange, are continuing to grow as the technology matures. Information blocking, from a vendor and institutional lens, plays out in local community culture, trust, relationships, and differentials in health information technology investments (Savage, 2017). There is rich guidance in our recent and current history of promising federal, philanthropic, and public–private partnership initiatives to advance a culture of health, equity, and affordability for communities to meet local health goals, with an emphasis on social risk factors.

Federal Initiatives Contribute Best Practices and Insight

Community-focused initiatives under the Heath Information Technology for Economic and Clinical Health (HITECH) Act of 2009, including the Beacon Community and Community Health Peer Learning programs, brought tremendous momentum to the health information exchange networks across the country as well as healthy community collaboratives. Communities engaged with nonclinical care partners developed and tested new care models, and helped to align community goals around shared values and a common purpose.

The Beacon Community Program

Beginning in 2012, the HHS Office of the National Coordinator for Health IT (ONC) provided $250 million over 3 years to 17 selected communities throughout the USA that had already made inroads in the development of secure, private, and accurate systems of EHR adoption and health information exchange. Each of the communities, with its unique population and regional context, served as a resource to their region, actively building and strengthening health IT infrastructure and exchange capabilities within communities; translating investments in health IT to measure improvements in cost, quality, and population health; and developing innovative approaches to performance measurement, technology, and care delivery to accelerate evidence generation.

Outcomes of particular interest included these:

- Communities engaging nontraditional care delivery partners to ensure that connectivity extends to include the broader spectrum of care providers working in schools (MN), ambulances (CA, OK, and UT), public health agencies (CA, MN, NC, and OH), and long-term and post-acute care providers (NY, PA, and RI).
- Communities testing new models for community-wide health information exchange (HIE) capability by building or standing up community-based infrastructure and policies to increase the amount of data being shared and to provide community participants with access to patient-centric views of health information that will better inform their Beacon objectives (CA, HI, LA, MI, MN, MS, NC, OK, and RI).

Sustainability was a key feature of Beacon Communities, and many of them sought to identify other sources of funding so that they could continue the projects they started (NORC, 2015).

Community Health Peer Learning Programs

In partnership with Academy Health, ONC supported the Community Health Peer Learning (CHP) Program from 2015–2017, engaging 15 communities to identify data solutions, accelerate local progress, and disseminate best practices and lessons learned.

Collaborating with NORC at the University of Chicago, and the National Partnership for Women & Families, and with guidance from Key Advisors, the CHP Program helped participating communities to inform national strategy and align with other delivery system reform efforts driving toward better care, smarter spending, and healthier people. These efforts built community capacity to advance progress toward population health improvements through the expanded capture, sharing, and use of electronic health data from diverse sectors. CHP projects are featured here: http://www.academyhealth.org/node/4901.

CMS Center for Medicare and Medicaid Innovation

The CMS Center for Medicare and Medicaid Innovation (CMMI) funds the development of new payment and service delivery models in accordance with the requirements of section 1115A of the Social Security Act. Additionally, Congress has defined—both through the Affordable Care Act and previous legislation—a number of specific demonstrations to be conducted by CMS.

Congress created the CMS Innovation Center for the purpose of testing "innovative payment and service delivery models to reduce program expenditures … while preserving or enhancing the quality of care" provided to individuals who receive Medicare, Medicaid, or Children's Health Insurance Program (CHIP) benefits. Section 1115A provided $5 million in fiscal year 2010 and provides a total of $10 billion for these purposes over the fiscal years 2011 through 2019, as well as an additional $10 billion each decade thereafter (https://innovation.cms.gov/Files/reports/rtc-2016.pdf).

A recent program of interest is the Accountable Health Community (AHC) Model, which will provide nearly $124 million over 5 years for local community organizations to serve as "hubs" that link clinical and community services. CMS, like many others, recognizes that the biggest drivers of health and health care costs are often social, environmental, and other risk factors that are beyond the scope of health care alone and that typically go undetected in the clinical care system and, therefore, are not addressed by health care providers.

By addressing a critical gap between clinical care and community services in the current delivery system, it will be possible to determine the impact of social care spending on total health care costs and overall quality of care for Medicare and Medicaid beneficiaries in targeted communities (see CMS Innovation Center, 2017, https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2017-Press-releases-items/2017-04-06.html).

National Committee on Vital and Health Statistics (NCVHS)

In 2011, The National Committee on Vital and Health Statistics (NCVHS), a statutory advisory body to the Secretary of HHS, examined how communities can become learning systems for health, and what resources exist and are needed to help them (https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/110208sm.pdf). Its Community Health Information Project is a response to the continued growth of leading-edge community health initiatives, juxtaposed against the reality that many communities have difficulty taking advantage of or sustaining these new opportunities.

Two HHS initiatives, the Community Health Data Initiative and the Learning Health System project, sparked NCVHS's interest in community-based health activities. The 2011 NCVHS workshop identified questions about: (1) how to improve local capacities, (2) how to improve how health data informs local work,

(3) how to protect individual privacy, and (4) how to realize the benefits of standardization without undermining local autonomy.

NCVHS began to envision large, interactive local networks, enabled by accessible and easy-to-use information and infrastructure, empowering communities to use data to enhance the quality of community life and improve local health. The infrastructure could strengthen the alignment of local, state, and Federal population health activities, and by its nature, requires a publicly (or jointly) supported infrastructure of standardized data, measures, and tools. While interoperability of health data at the person and community level was not an explicit objective, it is an interesting question to bring forward from this important work.

NCVHS continued to study the community health improvement movement from 2011 to 2016 and identified a need for a more strategic federal role to support communities, including improving the availability and access to data at the sub-county level for communities to drive health improvement efforts. Through the convening of workshops, roundtables, and environmental scans, six reports and one letter to the Secretary of HHS were developed.

These efforts culminated in the NCVHS Measurement Framework for Community Health and Well-Being, v4, released in January 2017 (https://www.ncvhs.hhs.gov/wp-content/uploads/2013/12/NCVHS-Measurement-Framework-V4-Jan-12-2017-for-posting-FINAL.pdf). This publication was supported by the NCVHS's Population Health Subcommittee, building on a year-long iterative process of public input. Domains and subdomains with examples of measures are included to stimulate and support community dialogue.

In its capacity as a Federal Advisory Committee, the Committee has turned over the Framework to a nongovernmental organization (NGO) whose leadership volunteered to steward its ongoing development, maturation, pilot, implementation, and ongoing refinement in collaboration with federal, state, local governmental, and nongovernmental organizations.

Institute of Medicine/National Academy of Medicine

In 2013–2014, the Institute of Medicine (2015), as part of the HHS Medicare and Medicaid incentive program for the Meaningful Use of HIT, was charged with recommending what social and behavioral information should be included in EHRs and identifying obstacles to the inclusion of such information. The two-phased IOM 2014 report "Capturing Social and Behavioral Domains and Measures in Electronic Health Records: Phase 2" (https://www.ncbi.nlm.nih.gov/books/NBK269330/) identified 12 social and behavioral factors most strongly associated with health and created measures for these factors (determinants) to be incorporated into electronic health records (EHRs).

Four of the 12 domains were recognized as already widely assessed in EHRs (race/ethnicity, tobacco use, alcohol use, and residential address). Eight domains were determined to be new, requiring additional work for measures inclusion

incentive program for the Meaningful Use of HIT. These new domains include: educational attainment, financial resource strain, stress, physical activity, neighborhood meaningful household income, depression, social isolation/connectedness, and intimate partner violence.

The work continued after the IOM was renamed the National Academy of Medicine (NAM). Another initiative (NAM, 2015) called Vital Signs: Core Metrics for Health and Health Care Progress proposed a set of 15 standardized measures, with recommendations for their application at every level and across sectors, to provide consistent benchmarks for health progress on high priority areas. The Committee that wrote the report envisions core measures as a tool for driving progress toward better health, better care, lower costs, and engaged patients and communities.

The need for linking the health of the individual and the health of the community, through better interoperability of health data to grow our understanding of social and behavioral determinants of health, impacting these reciprocal relationships has never been more profoundly needed, and perhaps ready for communities to consider taking on (Dzau et al., 2017).

Interoperability Roadmap Principles Guide Community Action

One of the remaining gaps for multi-sector community collaborations is to operationalize what health data interoperability means at a community level. What if multiple sectors, people, and organizations that support the public good, including healthcare providers, public health, and citizens themselves engaged in developing an interoperability roadmap for health improvement at the community level, recognizing the integral relationship of individual, family, and community health?

One possible place for communities to begin is to engage multiple stakeholders in dialogue about their knowledge, experiences, and current activities to support the ONC's 2015 Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap. The guiding principles in the Roadmap offer a framework for communities to evaluate their intentions and consider community-level actions that may sense for them. (See Table 16.3 for some suggested activities using the ONC framework.)

A December 2016 ONC report reviewed the year's strategies and accomplishments in building collaborative infrastructure for information sharing (https://www.healthit.gov/year-in-review). With the change of administrations in January 2017, it is not yet clear how much support for the Interoperability Roadmap will remain.

Table 16.3 Creating an interoperability roadmap at the community level

Guiding principles	Suggested community actions
Focus on value	1. Tap into the convening expertise of existing multi-sector collaborative(s) 2. Develop a value proposition for why health data interoperability matters at the community level (e.g., affordability, health equity, and community ownership). 3. Define the value from multiple perspectives 4. Link value messages to the 21st Century Cures Act
Be person-centered	5. Define current needs and barriers of health data interoperability for citizens 6. Develop education strategies that define health data interoperability across care settings and services 7. Define a set of measures for transparency of health interoperability 8. Report on progress: for individuals, families, providers, and community organizations
Protect privacy and security and respect individual preferences	9. Educate stakeholders and citizens about privacy and security of health data 10. Link education to related provisions in the 21st Century Cures Act 11. Assess the knowledge, spread and adoption of the Model Privacy Notice
Build a culture of electronic access and use	12. Assess the digital divide at a community level 13. Identify open access and distributed health databases available to the community 14. Encourage partners to share their self-reported interoperability adoption reports 15. Assess community incentives, culture, and barriers to information blocking
Encourage innovation and competition	16. Articulate demand for interoperability as a powerful driver to advance community vision 17. Encourage innovation, partnerships, and challenge contests for novel solutions
Build upon the existing health IT infrastructure and simplify	18. Quantify interoperability standards adoption and investments across community 19. Build on existing health IT infrastructure 20. Seek simpler solutions first
One size does not fit all	21. Each stakeholder does not need to implement the same technology for interoperability 22. Stakeholders should improve interoperability/usability for individual citizens
Adapted from:	HHS ONC, Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap, Final Version 1.0, December, 2015

Promising Initiatives for Community-Based Interoperability

Robert Wood Johnson Foundation (RWJF) Culture of Health

In 2014, the Robert Wood Johnson (RWJF) began to reallocate its funding portfolio in a major shift from grants and training programs in traditional biomedical, clinical, public health, and health professionals areas to a "culture of health," emphasizing the importance of cross-sector collaboration to promote health among all members of the diverse society that makes up the population in the USA (see https://www.rwjf.org/en/library/annual-reports/presidents-message-2014.html). This systems approach has helped to promote interest in the social determinants of health, has led to new approaches for training the next generation of leaders, and has resulted in many communities using local data to improve health and health care for their citizens. Many of those are profiled in the over the next few pages.

All In: Data for Community Health

All In is a nationwide learning collaborative that helps communities build capacity to address the social determinants of health through multi-sector data sharing collaborations. Recognizing that most of our data and interoperability infrastructure is based in clinical care settings, this initiative supports community collaborations that are working to integrate data that influences individual and community health—from other sectors including housing, education, economic development, and safety. All In was founded by two national initiatives, Data Across Sectors for Health (DASH) and the Community Health Peer Learning (CHP) Program, and leveraged by joint collaboration with the BUILD Health Challenge and the Colorado Health Foundation. All In currently includes over 50 community collaborations across the country (https://allin.healthdoers.org/).

Community Health Peer Learning (CHP) Program

AcademyHealth, with its partners from the National Partnership for Women & Families and the National Opinion Research Center (NORC) at the University of Chicago, built community capacity to link critical information within and outside of health care to address population health challenges. Funded by the Office of the National Coordinator for Health Information Technology (ONC), the CHP Program aimed to advance progress toward population health improvements through the expanded capture, sharing, and use of electronic health data from diverse sectors. The initiative engaged ten Participant Communities and five Subject Matter Expert Communities in a peer learning collaborative to support the identification of data solutions, acceleration of local progress, and dissemination of best practices and lessons learned.

From June 2015 to July 2017, program participants received awards of $100,000 to engage in a 17-month process to concrete and high-impact Community Action Plans (CAPs) for improving community health through the expanded collection, exchange, and use of health data. Their efforts ranged from pediatric asthma to housing insecurity, with technical assistance in data governance, community engagement, infrastructure, and sustainability (http://www.academyhealth.org/about/programs/community-health-peer-learning-program).

Data Across Sectors for Health (DASH)

Robert Wood Johnson Foundation launched Data Across Sectors for Health (DASH) to identify barriers, opportunities, promising practices, and indicators of progress for multi-sector collaborations to connect information systems and share data for community health improvement. Recognizing that the sheer volume and velocity of health data is unprecedented, this effort is aligned with several RWJF supported strategies to bridge health and health care and create a culture of health and equity.

In the fall of 2014, RWJF launched the Data for Health initiative and its advisory committee hosted a series of listening sessions, "Learning What Works," in five cities across the country. These led to recommendations about public awareness of the value of data use and exchange; building trust and capacity; and integration of health and social data.

The DASH National Program Office (NPO) is led by the Illinois Public Health Institute (IPHI) in partnership with the Michigan Public Health Institute (MPHI). The DASH NPO is assisting ten grantees in communities across the country as they develop, implement, and evaluate multi-sector data sharing projects addressing a range of public health challenges—together increasing the impact of community data sharing efforts on community health outcomes (http://dashconnect.org/about-dash/).

BUILD Health Challenge

The BUILD Health Challenge supports partnerships taking Bold, Upstream, Integrated, Local, and Data-driven approaches to community health at the local level. This initiative encourages communities to build meaningful partnerships among hospitals and health systems, community-based organizations, their local health department, and other organizations to improve the overall health of low-income residents. The BUILD Health Challenge funds implementation and planning grants and will provide technical assistance in policy development, monitoring, and evaluation.

Funding is provided by a set of partners that came together across sectors and geography: The Advisory Board, Blue Cross and Blue Shield of North Carolina Foundation, de Beaumont Foundation, Colorado Health Foundation, Episcopal Health Foundation, Interact for Health, The Kresge Foundation, Mid-Iowa Health

Foundation, New Jersey Health Initiatives, the Robert Wood Johnson Foundation, Telligen Community Initiative, and the W.K. Kellogg Foundation (http://buildhealthchallenge.org/).

The Colorado Health Foundation, Connecting Communities and Care

As part of the Colorado Health Foundation's larger strategy of supporting communities to prevent disease and improve population health, the Connecting Communities and Care funding opportunity supports and accelerates existing partnerships to create community health beyond the clinical setting by linking resources and programs between health care providers and communities. The initiative currently supports 14 collaborations for up to $200,000 for 2 years, to improve connections between community-based resources and the health care system to improve community and population health. Efforts are focused on linking assets to address health priorities; impacting obesity, mental health (including substance use), diabetes and/or heart disease; and upstream factors that contribute to health (http://www.coloradohealth.org/funding-opportunities/funding-opportunity-connecting-communities-and-care).

ReThink Health

ReThink Health is the flagship initiative of the Rippel Foundation and was founded in 2007 by some of the nation's leading thought leaders and innovators in health, economics, business, politics, and energy. The initiative works with communities and place-based initiatives to design build capacity and test strategies for community transformation by developing practical models, tools, processes, and coaching strategies that will help to transform local health systems.

In 2016, the initiative conducted a national Pulse Check (survey) of 237 multisector partnerships to learn how they have organized and financed their partnerships and also to distinguish the developmental phases they have experienced as their efforts have matured. It also produced a guide for local innovators and organizers in how to redesign and integrate health and social care at the regional level (https://www.rethinkhealth.org/).

Summary and Conclusions

We are in the midst of two shifts away from the medical model in health care delivery. One shift is from an exclusively provider-focused perspective to a consideration of the roles and perspectives of consumers and their family members and caregivers. Another shift is an increasing recognition of the role of community risk factors on individual health. We now recognize that most social and behavioral determinants of health and health status are influenced by actions and encounters that occur

outside the traditional walls of institutional settings, including the home, places of employment, retail clinics, and the neighborhood itself.

These shifts require a high degree of information sharing between individuals, providers, and organizations and therefore a high degree of interoperability between many different types of health IT, so that systems can exchange and use electronic health information relatively easily. Some describe this kind of ecosystem as a "nationwide learning health system"—an environment that links the care delivery system with communities and societal supports in "closed loops" of electronic health information flow, at many different levels, to enable continuous learning and improved health. This kind of system allows individuals to select platforms and apps to share and use their own electronic health information to meet their needs without undue technical, legal, or organizational constraints.

The current challenges for multi-sector community health collaboration involve the design and implementation of interoperable electronic information systems that follow patients and clients across a variety of health care and social settings. The fragmentation of funding has led to multiple and sometimes conflicting guidance about information sharing and distributed community infrastructure to implement interventions that can bridge institutional- and person-centric approaches. The vision for the future of interoperability is that information about an individual that is held and curated by different health and social settings can be aggregated in real time at the point of care, thus providing a comprehensive view of the person's demographic, social, and medical information, including medical history, allergies, current medications, family supports, food security, and other relevant and useful information.

It is not yet clear how best to invest in distributed community infrastructure and implement information system interventions that will last long enough to create sustainable change, but many funders and communities are looking for ways to do just that. We are excited about the future opportunities for people to engage with their community leaders, neighbors, provider organizations, and other stakeholders to build, promote, and help maintain healthy communities.

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Chapter 17
Ethical Issues in Consumer Informatics and Online Content

John Wilbanks

Introduction

After the revelations of Edward Snowden, and the elections of 2016, ethical issues in consumer informatics and online content finally began to rise to the level of public consciousness. Yet, the vast majority of consumer informatics applications continue to ignore ethical issues in favor of business considerations such as low transaction costs and frictionless enrollment and engagement strategies.

Software developers typically focus on minimizing the ability of their potential users to understand how the data is captured, how it is processed, and who owns the data in the end. This culture supports a set of business models in software development that depend on post-hoc uses of data to bring in revenue—most of which are advertising or surveillance based.

The end result of this transactional approach to ethics is a sea of data captured about us as we use our digital devices, phones, and credit cards. This data moves about without our agency, and usually without any right of ours to scrutinize the system or flow. It also enables the emergence of a surveillance culture of government, in which the ability to sensitively profile any citizen is achievable with just a few clicks in key corporate databases.

However, early returns from data collection in regulated informatics—clinical observational research—indicate a path forward, where the same tools used to design software are used to design ethical interactions. Using ethnography, personas, user stories, and other tools of interaction design, we see a path that balances the data collection of contemporary digital technology with concepts of autonomy, informedness, and the treatment of users as citizens with equal rights to their data.

J. Wilbanks (✉)
Sage Bionetworks, Washington, DC, USA

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State of Consumer Data: Endless Terms of Service and "Dark Patterns"

As our lives have moved more and more into digitally mediated spaces, we are subject to more and more interlocking contracts we sign in order to access technology—the terms of service. At the same time, the business models that fund the creation of that software has become more and more dependent on returns emerging from user data, rather than annual or lifetime sales models.

Two trends emerge from this context that merit exploration. First, the legal agreements surrounding technology have expanded in size and scope, and cover every scrap of software code that we touch over the course of a day. An average internet user would need to take 76 vacation days from work per year to read all the relevant privacy policies alone, ignoring all the terms of service![1]

Unsurprisingly, we have developed a culture in which we do not prioritize reading the legal agreement before we sign it when it comes to digital devices. A recent study called "The biggest lie on the internet" analyzed precisely this behavior. Reading an average privacy policy should take 30 min based on average reading speed, but instead took 73 s, where terms of service took 51 s yet should have taken 16 min (Obar & Oeldorf-Hirsch, 2016). As an additional sting, terms of service in this study included clauses advertising data sharing with the National Security Agency and potential employers, and requiring the donation of a first-born child in return for access.

In addition to the cultural pressure to click "Accept" without reading, physical differences exist when we read on screens versus in print: Web market research using eye gaze tracking finds that most users read half or less of the text on screen, that a vast majority scan text by skipping around the page, and only a small percentage read word by word (Weinreich, Obendorf, Herder, & Mayer, 2008).

A second trend emerges from the presence of savvy designers under pressure to maximize "engagement." "Dark patterns," which trick unsuspecting users into actions they would not normally choose, represent deceptive practices that interact with complex terms of service and privacy policies to trap users of consumer technologies in agreements that take advantage of their data (Brignull, 2013).

Dark patterns have a long history. A familiar pre-Internet example is the deceptive marketing practices of Columbia House mail order music, where participants were charged extremely high rates for music they did not want if they forgot to specify their choices. Known as negative billing, this dark pattern is nearly a 100 years old. Harry Brignull (2013) identified multiple types of dark patterns, including bait-and-switch, disguised ads, forced continuity, misdirection, and the roach motel, noting

[1] The Cost of Reading Privacy Policies: http://lorrie.cranor.org/pubs/readingPolicyCost-authorDraft.pdf. Researchers reviewed the top 75 websites on the Internet and found that the median length of their privacy policies was 2514 words. Then, they added another factor—how long it took an average person to actually understand what they were reading, which they found by giving simple comprehension questions to 212 study participants. http://techland.time.com/2012/03/06/youd-need-76-work-days-to-read-all-your-privacy-policies-each-year/.

their connection to longstanding heuristics of good design. Designers take these patterns and make them scalable, visually complex, and difficult to avoid.

The emergence of internet-connected hardware devices—also known as the Internet of Things (IoT)—represents a perfect marriage of abstruse terms of service, dark patterns, and the business models they support. Akin to Gillette razors of old, the hardware is sold at a loss, paid for by the evergreen flow of data.

Interestingly, there may be an opening as a result of the Internet of Things to begin addressing the twin issues of metastatic legal agreements and dark design patterns. The more intrusive the devices, the more difficult to maintain the ignorance of the user base—it becomes much easier to think about the question of what is happening with the information. And interestingly, these devices are increasingly contemplated as a component of ethically regulated observational research (Haghi, Thurow, & Stoll, 2017). For the first time, the convergence of dark patterns and lengthy agreements fall under the scrutiny of an established regulatory and ethical regime that cannot be easily avoided.

Ethical Issues in Regulated Research

The process of informed consent is essential to enhance participant autonomy when deciding whether or not to enroll in a regulated clinical research study. The informed consent doctrine (e.g., Murray, 2012) has evolved from disclosing the potential risks associated with medical treatment to include "all pertinent information enabling one to make a meaningful decision," a mandate that can be overwhelming to prospective participants.

As with online terms of service and privacy policies, a set of dark patterns in "traditional" informed consent processes deserves scrutiny. Multiple studies have reported significant issues with comprehension or "informedness" after traditional informing interactions before enrolling in studies and trials:

- IC forms are long and complex—more than 20 pages on average, requiring more than 1 h to read (Kass, Chaisson, Taylor, & Lohse, 2011).
- Nearly, 70% of informed consent interactions ended with the participant signing but not actually reading the entire consent form (Lavelle-Jones, Byrne, Rice, & Cuschieri, 1993).
- Even with careful implementation of consent protocols, only half of all those consented could accurately describe what was going to happen to them under that consent (Schultz, Pardee, & Ensinck, 1975).
- Nearly, all participants believed they understood the trials in which they had decided to participate, but only one in three could later describe the trial's goals (Daugherty et al., 1995).
- Only 40% of the patients claimed to ever read the consent form "carefully" and the legalistic structure and language was correlated to poor long-term comprehension of study goals and outcomes (Cassileth, Zupkis, Sutton-Smith, & March, 1980).

– Readability of IRB approved forms consistently falls short of IRB standards on readability (Paasche-Orlow, Taylor, & Brancati, 2003).

Taken together, these elements interact with the existing culture of lengthy agreements and dark design patterns to create a very compelling trap for regulated medical research as it moves into digital devices such as phones and IoT. Regulated research then represents a potential testing ground for designers, ethicists, and software developers to work together to create a novel set of light pattern for ethical interactions with devices and data capture. However, the interactions that will emerge from this grouping will be different than those created in nearly every other element of technology development. These are interactions that intentionally expose friction, rather than intentionally hide it.

Clues to these patterns exist. Reading comprehension does appear to increase with certain actions, with implications for assisting "informedness" processes in e-consent.

First, prioritization of certain paragraphs and key words on the screen or on subsequent screens positively correlates with retention (Lorigo et al., 2008).

Second, addition of pictures has been shown to slow down readers, lengthening eye-text fixation (correlated to the "on task" nature of a picture, with the belief that the cognitive effort to relate the pictures and the text together slows the reading) (Beymer, Orton, & Russell, 2007).

Third, shorter forms have also been connected to both improve comprehension and higher consent rate (Wager, Tooley, Emanuel, & Wood, 1995).

Last, there is evidence that informedness "decays" over time and is greatest at the moment of consent. E-consent might allow the study to scale in terms of enrollment but also removes the human-to-human interaction where a study staffer might intervene to address comprehension and capacity to provide informed consent (Lavelle-Jones et al., 1993).

At Sage Bionetworks, we worked with the Electronic Data Methods Forum (EDM Forum) at AcademyHealth to develop an eConsent toolkit to support the creation of some initial "light patterns" for consent into clinical research. First, we interviewed stakeholders in the EDM Forum's collaborative network, including ethicists, technologists, scientists, patient advocates, clinical data specialists, and more to understand their challenges and requirements.

We asked questions such as:

– What are your goals in patient-centered research? How do they inform your ethical procedures?
– What kind of data are you collecting, and how are you storing and syndicating it?
– Has the structure of informed consent documents ever prevented secondary data reuse? If so, how?
– At what point do you see informed consent as "kicking in" during patient-centered research? At collection of data? At entering a registry? At syndication of data to researchers?
– What are the implications of broad or open consent in your work? How do they connect with e-consent?

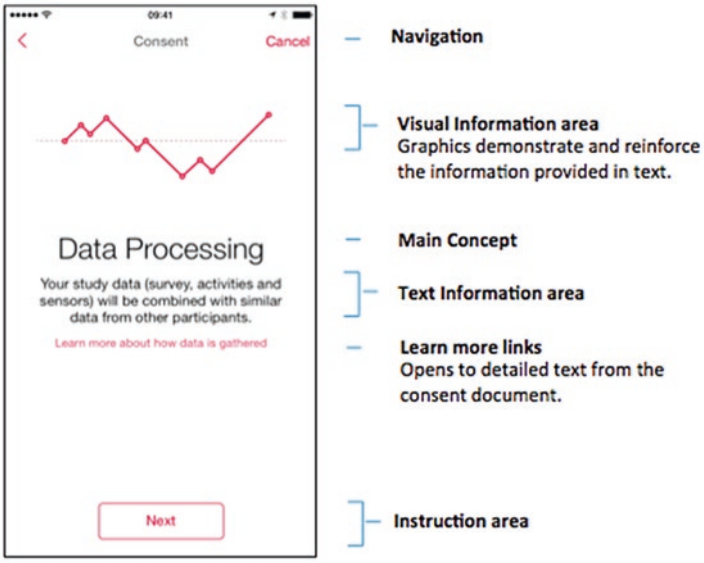

Fig. 17.1 Visual tier of consent screen shows the "data processing" concept

– Would you use a toolkit that provided prefabricated consent design and experience to enable your consent processes? What would you need to see out of that toolkit before you used or trusted it?

Emerging from these interviews, we created the Participant-Centric Consent Toolkit to help investigators create visual representations of consent forms. The visual representation draws on the implications of on-task pictures slowing reading comprehension, paired with clear, limited-length, large-font text, to increase comprehension (Fig. 17.1).

As we built the toolkit, we developed informal rules of thumb[2] for visual informed consent, including:

Use large icons related to the key study concept to occupy up to 30% of your screen;
Use 2–4 word text phrases describing the concept, to be placed underneath the icon to slow reading and fix attention on the concept;
Use text labels of less than 10 words, placed under the text slug;
Place no more than two links (other than "cancel") on the screen—one to learn more and the other to proceed to next screen; and.
Use simple, short text (less than 50 words) on secondary screens.

The visual representation takes a narrative form. Each screen displays an essential study concept, so that a succession of screens combines to describe the study's key features. Concepts cluster into classes such as research activities, data handling,

[2] Rules of Thumb. http://sagebase.org/pcc/participant-centered-consent-toolkit/rules-of-thumb/. Accessed October 19, 2015.

Fig. 17.2 Combined screens form a narrative layer atop an informed consent document

impact on participant life, participant rights, free will, and potential risks and benefits, issues to consider. Each concept screen has an on-task icon, a large-font "slug"[3] of one or two words indicating the concept, a text "label" of a sentence or two, and a "learn more" link. Clicking "learn more" generates a simple text screen whose navigation reverts to the main concept for reinforcement. When combined, the screens form a visual narrative that acts as an interface to the consent, to facilitate participant enrollment decisions (Fig. 17.2).

Benefits of Participant Centricity

All interactions that leverage digital devices exist in an attention economy (Goldhaber, 1997) that is not present in traditional clinical research. While it is significantly easier to recruit and enroll participants using these kinds of methods, retention and engagement become significantly more difficult. For most studies that use mobile devices, even consenting tens of thousands of participants does not yield large participation in data collection only a few months after enrollment. These samples are also not particularly representative, as early mobile studies show a significant bias towards young, male participants.

Taking a user-centered approach towards informed consent yields both an interface that is consistent with ethical obligations and existing regulations on human research, as well as indicating a path forward for general consumer data capture that

[3] "The keyword or slug (sometimes more than one word) clearly indicates the content of the story." *Associated Press: 2008 Stylebook and Briefing on Media Law,* ISBN 978-0-917,360-52-7, p.404

does not rely on misdirection and obfuscation. It is entirely possible to both craft short, readable text about clinical studies as well as to apply design resources to clearly reveal facts and details about clinical studies. It simply is a matter of willpower and time.

There may also be a degree to which this is a competitive advantage. In clinical research, moving to digital devices appears to increase enrollment, but does not lead to long-term and sustained engagement with the devices or the mobile apps (McConnell, Shcherbina, Pavlovic, et al., 2017).

The challenges of attempting mobile clinical studies include bias in selection, poor retention, self-reporting biases, and more (Chan, Wang, Tignor, et al., 2017). Thus, it is possible that mobile studies attempting to leverage dark patterns and complex agreements may suffer more attrition in their recruited participant base than studies leveraging intentional design.

Rigorous controlled experiments, as well as retrospective analysis, will be essential to understanding the subtle difference between unintended friction in consent design (which is undesirable) and friction working as designed to enhance participant informedness.

Emerging Trends and Future Directions: Nothing About Me Without Me

Consent, however, does not exist in a vacuum. It is deeply tied to the governance of the data that is collected. Traditionally, consent was obtained to extract the data from the individual, and that was the end of the relationship. Most of contemporary non-electronic consents reflect this transactional nature. However, participants in clinical studies have begun to demand a different social contract, one encapsulated in the phrase "nothing about me without me" (Delbanco, Berwick, Boufford, et al., 2001).

Nothing about me without me implies a relationship that is far more equal than the traditional asymmetric researcher to patient one. It must be addressed in consent, and its absence is often felt in consent interactions and clinical protocols that treat individuals as subjects. Designing study and technology governance that empowers the participant by giving them copies of their own data, easy ways to manage their study enrollment, research results, and the ability to directly contact the scientists running the study—these are all elements of participant interaction that must be addressed in contemporary clinical study. And, each of them impacts the consent design.

Meeting the participant community halfway can be complex. Most research institutions and funders do not have supporting structures that facilitate these new kinds of interactions. At a minimum, those running studies should give a full and complete copy of data back to every participant on demand. Designers should also ensure that the ability to withdraw, pause, and otherwise modify participation is easy to find within the user interface, rather than being buried at the bottom of complex nested menus.

In addition, our engagement with participants during our consent design process made clear that many participants want their data broadly available beyond the initial study that collects it. As participants become aware of the value of their data, more and more will demand giving the power to make that data broadly available.

In our own studies at Sage Bionetworks, we provide a "donate broadly" option to all participants. More than 70% of our enrolled participants elect to share broadly, and we launched data sharing in March 2016, in advance of our own data analysis publication (Wilbanks & Friend, 2016) and now have more than a 100 external data users actively analyzing the data. And, the "donate broadly" concept sits at the heart of the NIH's flagship Precision Medicine Initiative, where the AllOfUs Program will enroll participants specifically into a broadly shared data enclave intended to support the ongoing research and participant collaboration.

The nothing about me without me concept contains many possibilities, including making it simple for participants to download their data, or donate it to organizations that share on their behalf, or synchronize it with their accounts at companies that maintain other health data and services. These will become an essential element of participant engagement and study governance, and may begin to bleed over into consumer informatics and data capture as health and consumer trends begin to merge.

Summary and Conclusions

Informed consent sits at a crossroad. As data collection becomes more and more digital, informed consent can either adapt and become a design priority in the new world, or be treated as part of the one-click consumer agreement universe. Either way, the devices are coming—they simply represent too powerful of a data collection method, and too strong of an enrollment method, to stay out of the research space.

The early work on participant-centered consent represents simply the first step on a complicated journey towards designing rich interactions for clinical research and ethical individual engagement. We need a multiyear program to investigate the efficacy and desirability of various types of consent interactions, and a public effort to benchmark and evaluate these methods in different contexts with different populations. Without such an effort, it is very difficult to understand if an informed consent implementation is actually working or not. And, without such an effort being public, it will be easy for stakeholders to obscure the efficacy of their processes.

However, there remains a self-interest element to adopting ethical consent procedures beyond regulated research. As citizens are more and more bombarded with digital technology choices, those choices that present clear and ethical relationships over time may possess a sustained competitive advantage. Because the real challenge is not getting someone to install an application, or allow data collection. The

real challenge is working with someone to keep the application and data collection going over a long period of time, and to remain willing to perform study tasks in ways that provoke an understanding of health and wellness. Starting with a clearly ethical interaction is by far the best way to start that long-term, and we need free and open-source tools to support as many of those interactions as we can design.

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Chapter 18
Open Science and the Future of Data Analytics

Juergen Klenk, Philip R. O. Payne, Rasu Shrestha, and Margo Edmunds

Introduction: Touring the Big Data Landscape

"The power of machines to ask a trillion questions where a scientist can ask just 10 is a game-changer," says Robert Darnell, the founding director of the New York Genome Center and a physician scientist at The Rockefeller University in New York City, in Science Magazine (Science News Staff, 2017).

The health sector is teeming with data as more pen- and paper-based operations and processes are digitized, creating rich stores of information captured from multiple sources—electronic health records, clinical trials, genomic data, and health data from mobile devices, wearables, and the "Internet of Things."

More biomedical data are produced every year than at any other time in history. According to SINTEF (2013), fully 90% of all the data in the world has been generated over just the last 2 years. A recent paper in the Harvard Business Review pointed out that a total of 2500 petabytes of data were generated every day in the year 2012 alone and estimated that as much data is now generated in 2 days as was created from the dawn of civilization (Shah & Pathak, 2014).

The University of Pittsburgh Medical Center currently has about 8.9 petabytes of data in real-time storage, and this amount is doubling almost every 18 months.

J. Klenk (✉)
Deloitte Consulting LLP, Arlington, VA, USA
e-mail: jklenk@deloitte.com

P. R. O. Payne
Informatics Institute and Division of General Medical Sciences, School of Medicine, Washington University, St. Louis, MO, USA

R. Shrestha
UPMC and UPMC Enterprises, Pittsburgh, PA, USA

M. Edmunds
AcademyHealth, Washington, DC, USA

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Table 18.1 Orders of magnitude of data

1 kilobyte (kB) = 1000 bytes	1 petabyte (PB) = 1000 TB
1 megabyte (MB) = 1000 kB	1 exabyte (EB) = 1000 TB
1 gigabyte (GB) = 1000 MB	1 zettabyte (ZB) = 1000 EB
1 terabyte (TB) = 1000 GB	1 yottabyte (YB) = 1000 ZB

Source: Authors

The industry is talking about not just petabytes, but exabytes and zettabytes of data. Data explosion worldwide is projected to reach 40 zettabytes by 2020, with a 300-fold increase from 2005 (Gantz & Reinsel, 2012), doubling about every 2 years. If you are keeping track anymore, a zettabyte is one sextillion bytes, or one million petabytes. That is a lot of data (see Table 18.1).

IDC, which publishes annually on the growth of data, shows that healthcare not only makes up the bulk of the digital universe, but that it is growing at a rate of 48% each year (EMC, 2014). Genomic data is one of the fastest growing datasets in the world. A quick analysis (Robison, 2014) shows that a complete human genome, right off the sequencer, is about 200 gigabytes. Recent public and commercial enterprises such as All of Us (NIH, 2017) and AstraZeneca (Ledford, 2016), which attempt to sequence millions of genomes, quickly run into storage needs in the hundreds of petabytes or even exabytes, and this does not factor in the data created when analyzing and using this information. If we wanted to sequence the entire population, multiply the 200 gigabytes by Earth's population (approx. 7.6 billion in October 2017) to get about 1.4 zettabytes, or almost 10% of the estimated size of the digital universe in 2017 (IDC, 2014).

With healthcare focusing on value-based care paradigms that demand quality, efficiency, and effectiveness, data-driven decisions are of paramount importance. But, intelligent decisions are best made with data that gives us rich context, and a fuller view of all parameters and possibilities. How do we not drown in all this data we are generating? How do we stay afloat, swim, and surf—harnessing the tremendous power of this valuable resource? In other words, how much of this data is really meaningful, useful, or actionable?

As the healthcare industry marches on from analog to digital, we are seeing a massive proliferation of data sources, often siloed, often not talking to each other, and almost always created to address just a defined set of proprietary use cases. We are also witnessing an influx of data from new places, such as patient- or device-generated data, which we have yet to learn how to integrate and use. Clinicians often find themselves playing the role of a detective, navigating from one clinical system to another, piecing information together around their patients.

Researchers seeking to integrate data sets from different sources encounter a variety of barriers, including legal and ethical challenges to releasing data to third parties, as well as technical challenges in interpreting data that are not in shareable formats or where their provenance is unclear and documentation is missing or not available (Borgman, 2012).

As such, we increasingly find ourselves in an environment that is data rich, and information poor. Data volume alone simply does not equal insight or actionable information that advances science and discovery.

Data only become valuable when researchers and clinicians are able to connect dots and bring new discoveries to light so that they can influence practice and policy. That is the goal of open science and the topic of this chapter, which will assess the current state of open data, data sharing, and the emerging approaches that encourage open science and all it has to offer.

Data Liquidity as a Foundation for Analytics

Analytics turn data into useful information by using a range of tools and methodologies to discover, interpret, and communicate meaningful patterns. These tools work only when data is accessible and interoperable—or "liquid." Over the past decade and more, medicine has made steady progress in moving from paper and film to digital and filmless. However, we still find ourselves struggling with multiple disparate silos of data that do not do much more than just sit there and collect even more data that are not easily accessed. Often, these data silos have proprietary logins that lock the data to the application layer from their respective vendors.

The movement of the data is typically unidirectional, unextractable, and therefore not useful for analytic purposes. In a KLAS Research study on accountable care that looked at the information technology (IT) solutions needed for an accountable care organization (ACO) (Shrestha, 2012), it was found that analytics were at the top of the list.

A global survey of more than 3000 business executives to identify obstacles to widespread analytics adoption (Kruschwitz & Shockley, 2010) found that the ability to get the data was reported as the leading limitation. From the perspective of industry leaders, data interoperability is not just a "nice to have" feature anymore. It is a strategic imperative, and data analytics is a differentiator for top-performing organizations in healthcare and other industries.

Achieving a level of data interoperability enables a number of key functions that essentially are performed at the "above the electronic health record (EHR) level," such as enterprise analytics. Data from multiple disparate information systems need to be woven together to derive meaningful operational and clinical insights that drive actionable workflow within health systems and across the healthcare enterprise.

However, the sheer volume of available medical data has long outstripped the capacity of the most intelligent teams of clinicians and researchers to absorb and make sense of. Even the most powerful supercomputers struggle to keep pace.

Take cancer—an incredibly complex and protean disease. While scientists have successfully sequenced the human genome, and know that genomic variants are responsible for many cancers, they still do not know what genomic expressions are actually telling us. Genomic variants in tumors change dynamically over time and are often interdependent and can follow a pattern that is still poorly understood.

These patterns are integral to personalizing treatment to optimize individual outcomes, and yet they are still elusive. Getting the right data or information to the right person at the right time in the right format and medium to inform cancer care is still an unsolved challenge that requires liquid data and analytics so that providers can make optimal decisions for their patients.

Furthermore, new data streams from continuously emitting devices such as wearables and implantables have the potential to exponentially increase the volume and velocity of data in ways that will disrupt the way we collect data. The volume and real-time nature of these patient- or device-generated data will have serious implications across the entire field of life sciences and health care. Envision a scenario in which a patient's health status is monitored around the clock, allowing for early detection and prevention of disease. Such "real-world evidence" can also be used to monitor treatments for safety and efficacy. Already, the FDA is investigating the opportunity to reimagine clinical trials using such "real-world evidence," an approach that could dramatically accelerate the development of new drugs (Brennan, 2017).

Scientists work with a sense of urgency knowing that lives depend on a greater understanding of disease and how to stop it. Today, bringing a new treatment from research lab to market typically takes 12–14 years and costs around $2.6 billion (Tufts Center for the Study of Drug Development, 2014)—a tragic reality for the one in three Americans who live with a deadly or debilitating disease (Milken Institute, 2012). If we want to accelerate research and achieve breakthrough discoveries faster, scientists need more: more of the right data, more data in the right format for better integration, and more timely access to data. We need to learn to remove the barriers that currently surround our data and allow the data to flow freely to where they are needed—complete data liquidity.

Augmented Intelligence as an Asset

Soon after the completion of the Human Genome Project (NIH, 2015), scientists were faced with the hard truth that understanding biomedical function and disease purely from genomic data is not possible. That is because the job is much too complex. Biomedical function is a combination of many factors, and the human body is a system that integrates all of these factors, such as the mechanical and chemical behavior of proteins at the molecular level. Furthermore, the human body is not a closed system—it is exposed to the environment and affected by behavior. Thus, understanding biology, diseases, and treatment options from data requires studying one of the most complex systems science has ever encountered. Any attempt to solve this challenge requires the most effective combination of human intellect and computational power.

Fortunately, advances in computational power have allowed the development of algorithms and systems that can intelligently and autonomously take on the bigger

data-crunching jobs the human brain cannot; this trend was predicted almost two decades ago (Binnig, Baatz, Klenk, & Schmidt, 2002).

Algorithms based on machine learning techniques allow computers to learn and continually improve their ability to make predictions based on added and analyzed data. The roles these intelligent tools play in biomedical research continue to evolve and are key ingredients to the rapidly emerging field of data-driven biomedical research.

We even see the deployment of such tools in our everyday lives. Artificial Neural Networks (ANNs) are utilized to recognize faces in photo apps. Taking it a step further in the healthcare field are systems such as IBM's Watson, which can read and understand clinical knowledge from millions of publications and utilize its knowledge to suggest diagnoses and treatment options.

Such machine learning and Artificial Intelligence (AI)-based systems are needed to make sense out of growing mountains of biomedical data and identify patterns that will advance our understanding of the complex biological systems that operate across the genomic, proteomic, and clinical levels to make up our bodies. There are several examples of machines developing novel insights from these galactic amounts of data, but experience continues to demonstrate the enormity of the challenge.

The term Augmented Intelligence has been coined for the shared effort between human and machine (Guszcza, Lewis, & Evans-Greenwood, 2017). Machines provide cognitive computing capabilities (machine learning and AI) to rapidly and intelligently sift through reams of data in search of potentially meaningful patterns, while humans provide their associative knowledge to try and make sense of those patterns. Conceptually, this idea is not difficult, but its implementation is extremely complex because of the degree of collaboration and harmonization of data practices and policies—and personalities—that is required.

Today, the preclinical stage of drug development is mostly a labor-intensive approach of testing chemical compounds against every possible combination of different cell type, genetic mutation, and other conditions related to a particular disease. Currently, only 35% of compounds enter the clinical stage of drug development, and of those, about 1 in 9 is approved and can help improve and extend health–that is a dismal 4.1% overall (Schuhmacher, Gassmann, & Hinder, 2016).

Examples of early success stories using cognitive computing and augmented intelligence in biomedical research can be instructive. For example, Aliper et al. (2016) detail how they trained Artificial Neural Networks (ANNs) to predict the therapeutic use of multiple drugs using gene expression data obtained from high-throughput experiments on human cell lines. As the first known application of deep learning to drug discovery using transcriptional response data, it could substantially accelerate the preclinical stage of drug discovery (Aliper et al., 2016).

As such, ANNs' applications in preclinical trials are an important example of how cognitive computing and augmented intelligence can reduce both cost and time in understanding diseases and developing treatments. One Carnegie Mellon study found that machine learning can cut the number of experiments performed in drug development by nearly 70% (Spice, 2016).

Consider geneticists studying the roots of autism. They know inheritance patterns suggest that the disease has a strong genetic component but have only identified genetic variants that can explain about 20% of all cases (Geschwind, 2011). Finding other variants, and indeed other mechanisms, that contribute to autism requires analyzing the data of 25,000 other human genes and their potential functions—an overwhelming task for human researchers.

"We can only do so much as biologists to show what underlies diseases like autism," explained the New York Genome Center's Robert Darnell in *Science* magazine (2017). Darnell joined computational biologist Olga Troyanskaya of Princeton University and the Simons Foundation in New York City to enlist the tools of AI to better understand autism. After combining hundreds of datasets showing which genes are active in specific human cells, how proteins interact, and where transcription factor binding sites and other key genome features are located, the team used machine learning to build a map of gene interactions and compared those of the few well-established autism risk genes with those of thousands of other unknown genes, looking for similarities. This effort, reported in *Nature Neuroscience*, uncovered another 2500 genes likely to be involved in autism (Krishnan et al., 2016)—a remarkable breakthrough in understanding the genetic basis for the disease.

Another example for an Augmented Intelligence effort is the Microbial Metagenomics Discovery Challenge, to be conducted in early 2018 by NIH's National Center for Biotechnology Information (NCBI) and Deloitte Consulting, LLP. It will combine the power of the crowd with computational algorithms, to identify both novel viruses and antibiotic resistance genes in metagenomes, by searching through NCBI's Sequence Read Archive datasets (NCBI, n.d.). Students from two universities (San Diego State University and City University of New York) will comb through the results of machine-identified DNA sequences to interpret their nature (e.g., bacteria, archaea, eukaryotes, or viruses). This crowd-based effort demonstrates how discovery can be accelerated using something akin to an Augmented Intelligence-enabled, citizen-science-based approach.

Augmented Intelligence can also advance biomedical discovery by accelerating our understanding of new data sources, such as lifestyle and environmental data, which could have as strong an influence on disease development and progression as genetics (Rappaport, 2016). NIH's All of Us Research Program (NIH, 2017) will gather data from one million participants across a wide range of racial, ethnic, geographic, and socioeconomic levels and age groups in an effort to accelerate understanding of how environmental, lifestyle, and genetic factors play out in individual health. All of Us is designed to lead to the discovery of paths that will deliver precision medicine using an unprecedented level of collaboration among multiple research and analytic teams.

These efforts demonstrate the power and potential of Augmented Intelligence in an open science setting. However, just as we have not yet reached a state of data liquidity, these efforts are still the exception and not the rule. The field of healthcare and life sciences is still constrained by a community that views Big Data and Analytics as a byproduct rather than imperative for its future. We need to shift these views and open up the field to fully embrace interdisciplinary thinking and approaches, and

invite Data Scientists and indeed Citizen Scientists as equal peers. If we allow this to happen, Augmented Intelligence has the potential to democratize the field of health care and life sciences.

Foundations and Impediments to Open Science

The open science paradigm, also described sometimes as a movement, has the potential to substantially increase the speed and impact of biomedical discoveries, our understanding of disease, and treatment and care decisions, by making the pursuit of these complex challenges a collective effort, possibly at a reduced cost.

The ingredients for open science appear to be at our disposal—unprecedented volume and variety of data, and broad interest and engagement of a large community. These ingredients represent an opportunity for a paradigm-shifting approach to discovery science, one in which we move away from the collection and curation of high-cost and project-specific datasets, in which a small number of hypotheses are tested, and toward a model in which large-scale and heterogeneous datasets are collected, integrated, shared, and interrogated in a high-throughput manner.

Given the promise of open science, it is reasonable to wonder why this approach is not more common and widespread. Unfortunately, a number of notable impediments in the contemporary environment preclude or inhibit the pursuit of open science. We already mentioned two such impediments—a lack of data liquidity and a lack of interdisciplinary thinking. More generally, these impediments can be grouped into three main categories:

- Regulatory/policy: Concerns about regulations on use of data for research vs. quality improvement and operations (common rule and HIPAA).
- Technology: Absence of suitable platforms, standards, and cybersecurity frameworks, causing concerns about high IT investment cost, excessive needs for customization, and lack of integrity protection of sensitive data and information systems.
- Behavioral/cultural: Legacy issues associated with "data ownership," by researchers and clinicians alike, driven by career development standards, IP concerns, lack of patient-centeredness, and a general lack of trust in a shared environment.

The most vexing of these impediments is the behavioral/cultural issue. It has been well documented that culture change is challenging and fraught with peril for early adopters and advocates of change. The path toward open science represents a fundamental culture change in the healthcare and life sciences communities, and we know full well that it will not be easy.

Over time, the benefits of and momentum behind open science paradigms can help overcome the inertia created by these impediments to addressing fundamental flaws associated with "traditional" and highly compartmentalized approaches to science. This momentum will likely be amplified by the way in which open science

democratizes access to and participation in scientific endeavors, thus supporting true communities of practice and the economy of ideas and thinking that such collaborative constructs provide.

Democratizing Data, Hypotheses, and the Research Lifecycle

Traditional approaches to science are often compartmentalized and result in datasets that are assembled and interrogated in order to answer a relatively small number of questions. Figure 18.1 illustrates this point for biomedical research, but the issue applies equally to healthcare research.

In the traditional research model, researchers often engage or otherwise recruit individuals or populations with certain characteristics of interest, from whom data of various project-specific measurements are generated. The researchers then pose a set of hypotheses concerning questions of interest relevant to this data and use any number of analytical methods to address them.

The output of this traditional approach is usually a set of formal, peer-reviewed publications, summarizing or justifying the methodological activities that have been employed. A defining characteristic of this approach is the pursuit of hypotheses and the generation of "downstream" publications that focus on a single or limited set of research questions.

Further, in this traditional model, researchers rarely share their datasets (with a few exceptions largely driven by evolving scientific publishing paradigms that involve the deposition of source data alongside publications). As a result of such

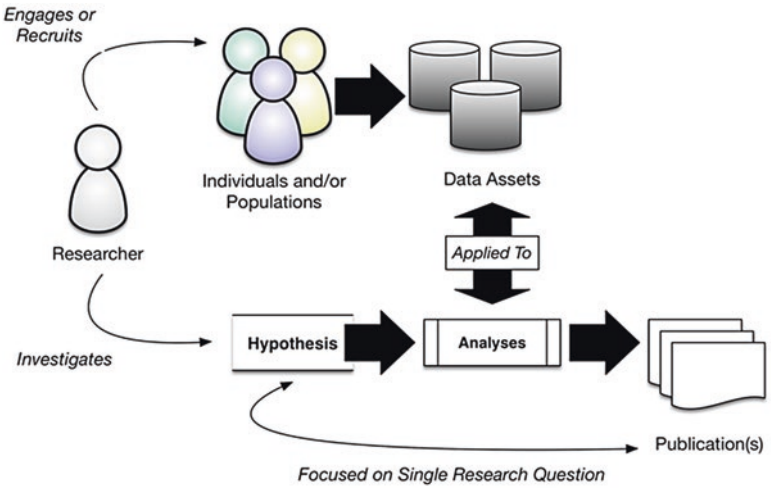

Fig. 18.1 Overview of the "traditional" research paradigm, in which data, analyses, and publications are highly compartmentalized and infrequently shared, leading to concerns surrounding research "reproducibility" and "rigor." Source: P. R. O. Payne

infrequent sharing, these data, and any methods applied to derive meaning from the data, are nontransparent to other researchers who cannot learn from or otherwise "build upon" that body of work.

This is the fundamental basis for current concerns about research "reproducibility" and "rigor," wherein many studies cannot be recreated after their publication (NPR, 2017). The lack of reproducibility calls into question the quality and veracity of the findings.

In contrast, open science places a much greater emphasis on the sharing, reuse, and transparency of data and analytical methods (Fig. 18.2). In the open science model, the traditional approach to research can remain intact, but the data assets and analytical methods are shared with a broader community of researchers.

The open process results in several positive additions to the traditional research model, including the following:

- With access to the right platforms and technologies, additional researchers can discover, adopt, and adapt research-generated data assets, particularly where their research questions are analogous or complementary to the originating researcher who generated the data and methods being shared.
- Researchers who are pursuing work surrounding shared data assets can generate and analyze multiple hypotheses. When a community of practice builds around shared interests, researchers are often informed by each other's work, thus enhancing the cumulative nature of such discovery science.

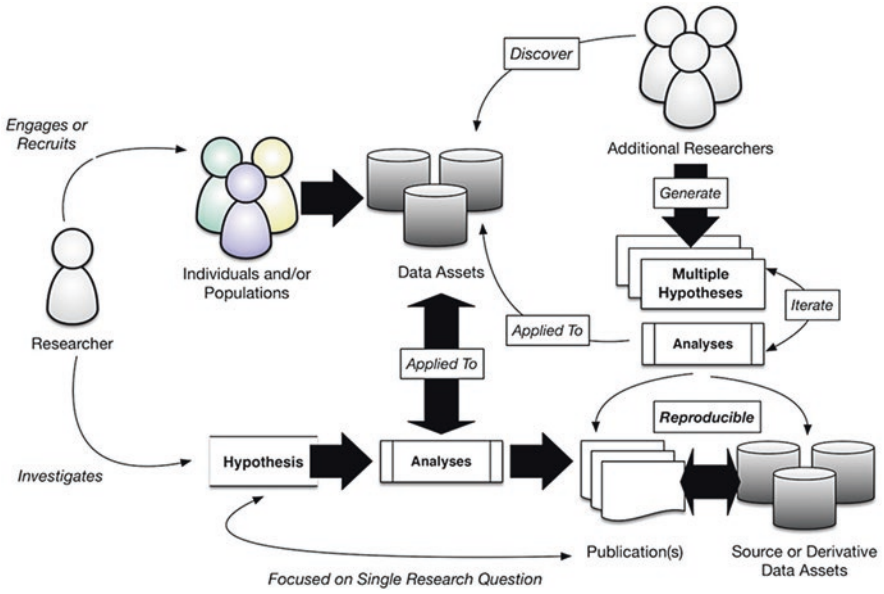

Fig. 18.2 Overview of an open science paradigm, in which sharing, reuse, and transparency of data lead to greater, cumulative impact. Source: P.R.O. Payne

- Additional and highly reproducible data assets and methods—And publications describing them—Can be made available to the healthcare and life sciences community writ large. This sharing enhances trust in research products (as a function of improved "reproducibility and rigor"), and also facilitates research that builds upon and is informed by prior efforts, rather than recapitulating prior efforts.

Overcoming Regulatory/Policy Impediments

Open science exists in a complex ecosystem. Policies and research standards associated with the protection of human participants, patient-level data privacy and confidentiality requirements (e.g., HIPAA, HITECH, etc.), local information systems security protocols, and a substantial variety of other requirements and best practices interact in a way that is often challenging to navigate.

While the regulatory frameworks are well-intentioned and aim to protect both critical human rights and sensitive technologies, their development over the last several decades has not always been well harmonized, and they often cause confusion or conflict when applied. As a result, individuals or institutions may attempt to control for real or perceived ethical, civil, or criminal risks by minimizing or eliminating circumstances in which such frameworks are subject to interpretation. This is most often manifested by the position that all data sharing is to be avoided unless it can be proven to be absolutely essential and effectively risk free.

While this absolutist position is the easiest to adopt in that it requires minimal effort and deliberation, it is also highly inconsistent with the principles of open science, and thus serves as a major impediment to more impactful, timely, and resource-efficient discovery science. In order to achieve the benefits of open science, the following steps should be considered:

- Simplify and harmonize conflicting data-sharing, privacy, and confidentiality frameworks at the federal, state, local, and institutional levels.
- Recognize the ethical imperative for institutions that possess data to leverage those data to improve the human condition, and therefore identify ways to better interpret and apply appropriate regulatory frameworks that support and enable data sharing (e.g., adopt data sharing as the default scenario unless proven to be infeasible).
- Develop and promote innovative ways to move the locus of control for data sharing away from institutional data stewards and toward patients and communities, enabling such groups to "donate their data" and thereby empowering individuals from whom such data are derived to be integral parts of the data-sharing enterprise.

These activities are both achievable and desirable and represent a high-priority research and practice agenda for the healthcare and life science community.

Overcoming Technology Impediments

To overcome the technology impediments, we will need to establish the technical underpinnings and best practices that will allow healthcare and life sciences practitioners to engage in open science without undue technical, financial, workload, and security burdens and concerns.

Several major efforts to address these impediments are under way. The National Institutes of Health (NIH) is piloting the NIH Data Commons (NIH Office of Strategic Communications, 2017), which is proposed to host all "digital objects of biomedical research" and make them Findable, Accessible, Interoperable, and Reusable (FAIR) (Wilkinson et al., 2016) for researchers and scientists.

The Data Commons creates the ability to openly share not just raw data, but all biomedical data, images, metadata, algorithms, etc. It will create a way for researchers to collaborate on the hardest problems, to share their digital resources, and to apply cognitive computing capabilities, all in one cloud-based environment. The FAIR principles will serve to establish widely accepted governance principles focused on data standards, annotation standards, sharing standards, and quality standards for these digital objects, a key foundational requirement for collaboration. The Data Commons also focuses on addressing other key technical challenges, including unique identifiers, security and identity access management, and ethics principles for sharing and collaboration.

The Data Commons will also help establish a collaborative environment that can stretch beyond biomedical researchers and include computer scientists, mathematicians, engineers, and many others. Digital biomedical research is a highly interdisciplinary field, and progress depends on the ability to bring together the most diverse minds.

Another effort to create a platform to share data is CIELO, which stands for "Collaborative Informatics Environment for Learning on Health Outcomes" (CIELO, n.d.). This collaborative project of AcademyHealth's EDM Forum demonstrates that a critical technology hurdle for collaboration is the need for a platform where important datasets can be integrated and harmonized, and where algorithms can be collectively developed and tested to advance treatment, research, and discovery. By bundling data and tools or methods, while also supporting the formation of scientific, social, and virtual communities-of-practice surrounding such bundles, scientists are far better able to pursue open science paradigms more efficiently and effectively.

The Observational Health Data Sciences and Informatics program (OHDSI, 2017) focuses on the need for a data standard to allow the integration of all digital objects into a common format for collaborative open science. As such, OHDSI is based on the OMOP common data model (OMOP, n.d.) and extends OMOP into a fully functional platform including analytics tools to provide a comprehensive Open science environment. An example for treatment pathways is provided in a recent article by Hripcsak et al. (2016).

However, the field is lacking large-scale support for creating and sustaining these types of platforms, technologies, and best practices. Ongoing efforts such as the examples provided above are still being treated as data science or informatics discovery science unto themselves, rather than as an evolutionary step toward better science and improved use of resources. Data have yet to be consistently recognized and appreciated as valuable assets, and until we achieve a complete shift in mindset across all of healthcare and biomedical research, a severe funding gap will remain. We must continue to find ways to increase the development, adoption, and sustainability of collaborative platforms, technologies, and best practices, while also promoting the value of open science, to achieve the needed breakthrough in support, both financially and culturally.

Overcoming Behavioral/Cultural Impediments

An abundance of legacy issues are associated with "data ownership," such as focus on publications for research and career development instead of sharing data, protection of data as proprietary assets to address Intellectual Property concerns, an underappreciation of patients as the true providers and owners of data, and a general lack of trust in a shared environment. These are the root causes that promote the sorts of behaviors that keep us stuck in science frameworks such as the traditional research model shown in Fig. 18.1.

For example, traditional incentives and standards often encourage and reward researchers for generating but not sharing their own datasets, pursuing and publishing on more narrowly defined research questions, and incentivizing predominantly the "first" or "senior" investigator roles. These paternalistic and reductionistic patterns are rooted in technical and cognitive constraints that existed at the dawn of modern science and scholarship, and that have remained largely unchanged into the present day. The patterns become clearly visible in the way grant money is distributed (Flaherty, 2017).

However, recent advances in our understanding of systems science and theories allow us to pursue previously unexplored and high-impact questions, and also demonstrate that reductionism rarely leads to discovery. Open science is a prime example of systems science in action, a form of crowdsourcing that allows large-scale communities-of-practice to coalesce around shared questions, data, and tools. This collaboration allows many scientists at multiple sites to pursue cumulative and multifaceted approaches to asking and answering critical questions.

Open science will require new incentives and "community standards" for scientific achievement. In the field of biomedical research, these include giving credit to investigators for sharing data and tools independent of traditional publications; creating and recognizing new publishing and evidence-dissemination models that involve large-scale teams of investigators working together (i.e., moving away from the emphasis on "first" and/or "senior" authors in such publications); and understanding

and supporting new career trajectories and pathways for team scientists who support and enable these types of collaborative research endeavors.

We believe that these issues are common across the academic, private sector, and government settings, but manifest themselves slightly differently. While the academic sector is mostly concerned with securing publication credits for career advancement, the private sector is more focused on securing IP protection for competitive advantage. All sectors exhibit a general appreciation for patients as the data providers, but an underappreciation for patients as the "data owners"—a general lack of patient-centricity.

More fundamentally, there is a basic lack of trust surrounding data, due to a perceived inherent value that may be lost when data are shared. We must find ways to overcome this lack of trust if we want to realize the promise of open science. In the following section, we will explore how an emerging framework—blockchain—can be employed to establish this necessary foundation for trust in a collaborative environment to allow data to be shared more freely.

Blockchain: A Framework for Trust

Greater openness and collaboration around data are necessary to drive research and discovery forward. This requires a new level of trust. Trust when sharing data. Trust when people come together around data. Trust in open science. Without trust, data and talent remain locked down by hidebound, expensive gatekeepers.

Achieving trust and greater collaboration will require understanding and acknowledging that data have an inherent value that can be traded fairly, similar to a currency. As we have seen, a faster, better process for assigning and verifying credit is needed to overcome frustrating barriers to data sharing that impede greater openness and faster progress. If biomedical research is to advance more quickly and effectively, it is imperative to break down the culture of cloistered science while adequately protecting intellectual property and the integrity of data's lineage.

One promising solution is blockchain—a decentralized and encrypted way of recording digital transactions. A blockchain is a distributed ledger that creates trusted pathways for the exchange of valuable goods—in our case, data. The ledger is managed through the consensus of networked participants, who add information about transactions (e.g., sharing or use of data) that are continuously tracked. Transactions are recorded as "blocks" with date–time and source stamps, and the blocks are linked and encrypted to form a chain that cannot be changed or controlled by any single entity.

Blockchains can be public, or private and restricted to certain members. When new information is added, every computer on the network is notified and updates its copy. The result is an expansive, tamper-proof, distributed source of truth.

Blockchain technology is used to keep track of digital currency transactions and is being explored for use in the financial industry. Because a blockchain provides a framework to track ownership, to exchange valuable goods (data), and to give credit

for offering valuable goods (data), it is a prime match for life sciences and healthcare research.

Blockchain's prevalence in international banking can provide confidence to those working in life sciences and healthcare to advocate for its use. The core issue the healthcare and financial industries have in common is that security is paramount. Everything recorded in a blockchain is impossible to change or manipulate since blockchains are inherently secure. Such a mechanism for trading and sharing data not only maintains but also clarifies the value of data.

Organizations are increasingly seeing blockchain's potential to advance the understanding of disease, accelerate biomedical discovery, and fast track the development of drugs. This is no surprise. Collaborating around an open-source, community-wide trusted ledger for digital objects of biomedical research enables more people to work together with more trust. Blockchain may hold the key to establishing the trust needed to promote open science, yielding benefits that can include the following:

- *Accelerating Precision Medicine*: Blockchain is "asset-agnostic" and thus provides the flexibility to "trade" a wide array of digital objects, including electronic health records, clinical-trials data, omics-based studies, daily observations of living, lifestyle information, as well as associated algorithms and code. The success of precision medicine—An emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle—Hinges on the ability to share, integrate, and analyze all of these data types in a trusted, collaborative environment.
- *Advancing Patient Centricity*: Blockchain offers the true "data owners"—Patients—The ability to better control the exchange of their health data as a shared, valuable asset. It would allow patients to have greater influence on the use of their data to advance treatment and care discovery and biomedical research in open science. This benefit extends to underserved and minority populations, offering greater access for many to participate in research.
- *Facilitating Contracts and Credit*: Blockchain-based smart contracts allow scientists to follow a project through its entire lifecycle to help determine when someone gets paid and credited for their work and ideas, and whether contracts or agreements are executed properly.

Healthcare leaders are recognizing these demonstrated benefits. An IBM Institute for Business Value survey (2016) of 200 healthcare executives—both payers and providers in more than a dozen countries—found that 16% expected to have blockchain at scale in 2017. Figure 18.3, from a recent report on opportunities for blockchain in healthcare (Krawiec, 2016), illustrates a sample mechanism of a blockchain for electronic health records (EHRs).

A June 2017 Frost & Sullivan (Versel, 2017) report details the significance of blockchain's immutability: "At its core, blockchain offers the potential of a shared platform that decentralizes health data, ensuring access control, authenticity, and integrity of protected health information" (data subject to HIPAA privacy and security regulations).

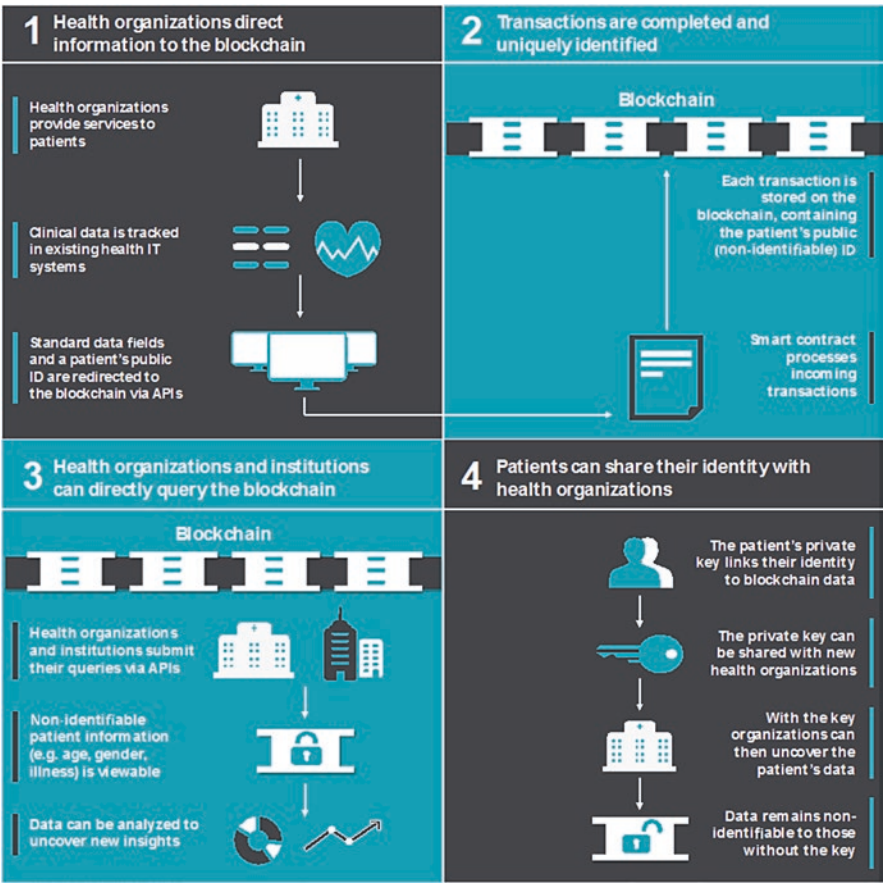

Fig. 18.3 Illustrative healthcare blockchain ecosystem. Source: Reproduced from Krawiec (2016) with permission

"Further, the blockchain-based distributed network consensus with cryptography techniques provides an additional layer of trust to minimize cybersecurity threats for healthcare IT systems. This never-before trusted workflow with a 'single source of truth' presents the healthcare industry with radical new possibilities for outcome-based care delivery and reimbursement models," the report's summary continued.

If traditionally conservative payers and providers are adopting blockchains, they clearly merit greater use in the life science and biomedical research sector. Imagine physicians, scientists, engineers, mathematicians, and experts from other fields with the potential to bring novel solutions to bear in solving biomedical research's most vexing challenges. These players could use blockchain to access and contribute to a wealth of data and information, collaborating in ways that currently do not exist.

As the source of truth and verification, blockchain provides a bird's-eye view for researchers into all inquiries, studies, and proposals surrounding a topic. Emerging applications illustrate its potential.

For example, in clinical trials, multiple stakeholders—research organizations, data safety management boards, sponsoring pharmaceutical companies, principal investigators, and regulators—all require access to analyze and review results. The report "Blockchain: An enabler for life sciences healthcare" (Roma, 2016) details how blockchain can create the ability for clinical-trial collaboration across interested stakeholders: "Adoption of a cloud-based blockchain system for storing and reporting clinical-trial results could significantly reduce the costs of holding the trial, while improving collaboration and transparency among stakeholders and provide a tamper-free view into the results" (as well as support electronic consent forms).

Ron Ribitzky, a Massachusetts physician who consults in precision medicine and health informatics, told GenomeWeb (Versel, 2017) that he expects it will take 5 years or more for blockchain to become commonplace in genomics. "What will push the issue, he said, is the combination of data volume that genomic studies generate, the velocity at which data hits a health system, and the rate of change in understanding genomic data itself." This is leading to what Ribitzky has dubbed the "paradox" of precision medicine: "The rate of discovering new precision medicine 'dots' overwhelms our ability to connect them," he said.

Continued open experimentation with the use of blockchain in health care and biomedical research is imperative. ONC's Blockchain Challenge (Siwicki, 2016) accomplished just that—it attracted more than 70 white paper submissions and projects. The submissions show the breadth of opportunities and highlight the challenges that will be instructive for policymakers and those working to accelerate discoveries and cures.

Open science is not just open sharing, but collaborating and connecting with others to ask key questions, try new combinations, exchange ideas for analytic approaches, gain a fresh perspective, and attempt, fail, and learn together, smarter and faster. Blockchain helps establish the kind of trust among collaborators that allows this kind of productive learning and discovery to flourish.

Implications of Open Data and Science for Workforce Development

Intrinsic to all of the arguments concerning the benefits of and challenges to achieving a vision of commonplace open science is the need to create and support an appropriately prepared workforce. We believe that there are three core competencies and two enabling activities that are central to doing so, as is illustrated in Fig. 18.4 and explored in more detail below.

- *Core Competency 1—ELSI of Using Open Data*: As was previously discussed, a complex environment of ethical, legal, and social implications (ELSI) surrounds

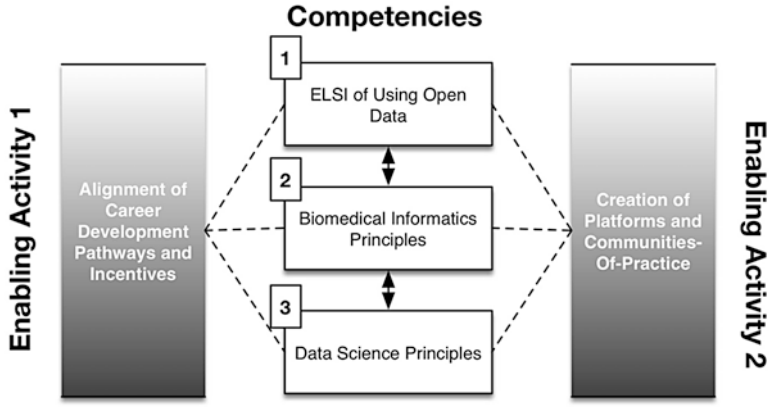

Fig. 18.4 Core components associated with creating an open-data and science-prepared workforce. Source: P.R.O. Payne

the creation and use of open data in the area of healthcare and life science, particularly in those instances where data are derived from humans. Accordingly, open science practitioners must be able to understand and apply relevant regulatory and ethical frameworks in a harmonized and responsible manner. This core competency extends beyond the traditional thinking concerning technical requirements for researchers.

- *Core Competency 2—Biomedical Informatics Principles*: The scientific field of biomedical informatics translates data into contextualized information and then applies such information as actionable knowledge. Translational theories and methods are discrete from but complementary to data science and are essential to addressing the community-building, evidence-generation, and collaborative investigation efforts needed to fully implement an open science workflow that addresses critical systems-level problems.
- *Core Competency 3—Data Science Principles*: Data science encompasses the broad range of "sense making" and reasoning operations that can be applied to heterogeneous data types in a way that is highly synergistic with biomedical informatics. This synergy can include methods such as those associated with applied mathematics, statistics, machine learning, and artificial intelligence, to name just a few. The primary objective of these methods is to identify meaningful patterns or "signals" in datasets so that hypotheses can be generated and/or tested.
- *Enabling Activity 1*—Alignment of career development pathways and incentives: As we have already noted, the current issues associated with "data ownership" are a substantial barrier to the open science paradigm. Therefore, to educate and prepare a workforce to pursue work following this paradigm, we will also need to realign the culture and environment in a way that enables their success. This transformation will involve deriving new metrics for measuring individual productivity and generated value, and creating pathways that reward team science.

- *Enabling Activity 2*—Creation of platforms and communities of practice: Finally, preparing an open science workforce will also require that we equip those individuals with the raw materials they need to pursue both their training and ultimate work. These raw materials will likely include: (1) forums for interaction with other individuals working in such areas as identified communities of practice; (2) mechanisms for discovering, adopting, and adapting large-scale open data assets; and (3) mechanisms for exchanging, modifying, and re-contributing novel data analytic tools and methods in a trusted manner. We believe that much of this type of platform and community building will happen in a virtual sense and will require the active participation of professional societies, funders, publishers, and practitioners working in a coordinated and integrative manner and focusing on the sustainability of this vital infrastructure.

Conclusion

> In God we trust, all others bring data.
> Attributed to W. Edwards Deming

We are witnessing the evolution of analytics capabilities in healthcare and life sciences pushed in large parts by industry challenges, and pulled in most parts by facets of value-based healthcare. Stand-alone tools that garner a focused level of insight into traditional volume-based metrics are not enough, and we are seeing broader capabilities that are able to leverage multivariate data from data warehouses expressed in much more real-time and distributed methodologies.

Data are invaluable resources that are often described as the "lifeblood" of any given industry. In many ways, the very essence of the conversation around data management has shifted with the availability of big data tools and capabilities. The debate today is less about whether we can afford to store information and more about whether we can actually afford to throw it away. With big data technologies now at our fingertips, and the cost of data storage having dropped dramatically over time, data in most instances should not be discarded. The focus today is moving from processing volumes of data that perhaps were just not previously practical to store, to dealing with massive amounts of data at a time, detecting insightful metrics, and responding quickly to emerging problems.

Big data technologies present a fresh opportunity in healthcare and life sciences to bring previously unfathomable amounts of data to life through open science, so that we can transform the data to valuable insights. This kind of open science, fueled by new tools, provides an opportunity to put the data to work for us. Big data technologies will illustrate novel ways to measure new discoveries, improvements in quality of care and improved patient outcomes and will drive efficiencies in biomedical research and clinical workflow with new insights that we did not know were possible to attain.

From a research perspective, the ability to run deep analytic queries on huge volumes of structured and unstructured data is a fundamental big data challenge. It

requires massive parallel-processing data warehouses and purpose-built appliances for deep analytics, as well as capabilities around Augmented Intelligence that are continuing to be perfected. Big data is not just about data at rest—it is about data that are also in motion.

Streaming data represents an entirely different big data problem—the ability to quickly analyze and act upon data while they are still moving. There has been much progress in this area, and the possibility of correlating data elements such as hours (or months) of live waveforms from the ICU with other types of data across the healthcare enterprise is an exciting one. Still, the curation challenges are daunting for streams of observations that are not bounded datasets, and new analytic tools, methods, and many new policies and practices need to be developed to enhance current efforts.

Meanwhile, we are seeing a merging of traditional and big data approaches to handling these data elements. If the traditional approach was structured and repeatable analyses, the big data approach is one of collaborative, iterative, and exploratory analyses. Big data then delivers a fluid platform to enable creative, collective discovery, and scientists jointly explore the facets and dimensions around the many ways intelligent insights could be asked or derived. This is open science at its best.

The opportunity at hand is to be able to scan these massive stores of data and connect them with other types of data that may be able to provide new insights and meaning. Correlating clinical data with cost, outcomes, and performance data, and then tying these to evidence-based guidelines and clinical best practices, could reveal entirely new insights and opportunities to continue to push the needle forward with newer care models. Similar opportunities exist in the biomedical research realm.

As new value metrics around discovery, quality, outcomes, and costs become better aligned with patient-centric workflows, a culture of collaboration, and a foundational layer of trust, we should see scientists embrace sharing data to drive intelligent decisions in an emerging open science ecosystem.

While we rejoice that the digital era is upon us, we should be concerned that we have not really been able to capitalize on the sheer power of the data that we have all around us. This chapter is a call to action; a cry for everyone in the health care and life sciences community to comprehend the power of data, increase their levels and types of collaborations, break down existing barriers and silos, and to actively seek the benefits that can be garnered from open science.

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Chapter 19
Is It Possible for the NHS to Become Fully Digital?

Julian C. Tomlins

Introduction and Overview

The National Health Service (NHS) is viewed as a national treasure in the United Kingdom (UK). The NHS treated its first patients in 1948 and was founded on the principles of meeting the needs of all, remaining free at the point of care, and providing access based on clinical need rather than ability to pay (Glover-Thomas, 2013).

The guiding principles are laid down in the NHS Constitution (Gov.UK, 2012a):

1. The NHS provides a comprehensive service, available to all
2. Access to NHS services is based on clinical need, not an individual's ability to pay
3. The NHS aspires to the highest standards of excellence and professionalism
4. The patient will be at the heart of everything the NHS does
5. The NHS works across organizational boundaries
6. The NHS is committed to providing best value for taxpayers' money
7. The NHS is accountable to the public, communities, and patients that it serves.

With the enactment of the Health and Social Care Act of 2012 (HSCA, 2012), significant changes from the traditional mission and culture of the National Health Service (NHS) became necessary. The new legislation was meant to force a modernization of the NHS to address increasing demand, due to the aging of the population and the increase in chronic conditions, and increasing costs of care due to new "more sophisticated and expensive treatment options" and higher costs of medication (gov.uk, 2012b).

The large-scale reforms driven by HSCA 2012 saw the creation of a National Commissioning Board to be known as NHS England to oversee the day-to-day running of the NHS. Across the country, 209 Clinical Commissioning Groups

J. C. Tomlins (✉)
Roche Products UK Ltd, London, UK

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(CCGs) have local responsibility for providing health services to meet the needs of their populations. The CCGs replaced the former Primary Care Trusts (PCTs), and all have General Practitioners (GPs) as lead members of their Executive Boards. In London alone, there are 31 separate CCGs to care for 8.2 million people at a cost of £15 billion in 2016.

The pace of change since 2012 has been unprecedented. Following the new legislation, the King's Fund was quick to say and rightly so that the "top-down reorganization was distracting and damaging; new systems of governance and accountability are complex and confusing; and the absence of system leadership is increasingly problematic when the NHS needs to undertake major service change" (Ham, Baird, Gregory, Jabbal, & Alderwick, 2015).

After the October 2013 appointment of former United Health senior executive Simon Stevens to lead the NHS, however, the new NHS has still been undergoing further reforms. These include the development of accountable care systems and other new care models that seek to improve care integration, as well as organizational changes to improve efficiencies and sustainability (see Fig. 19.1). Many argue that the previous reorganization during Tony Blair's tenure as Prime Minister had finally embedded by 2010 into a functional healthcare system only for it to be unnecessarily and expensively replaced by the subsequent Tory Government.

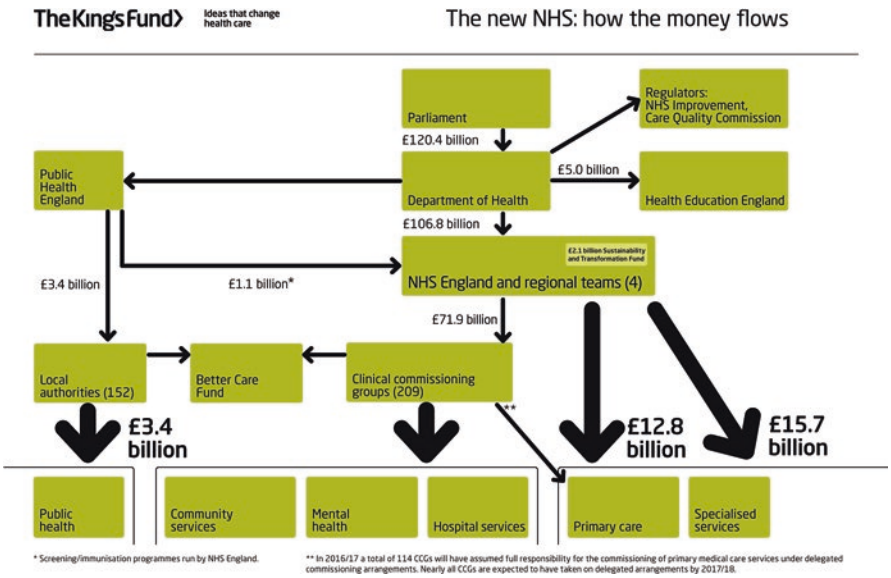

Fig. 19.1 NHS structure and funding includes Clinical Commissioning Groups that provide health services locally with funds received from NHS England. Specialized Services are directly commissioned by NHS England (including Cancer Services). The Better Care Fund enables integrated health and social care services to improve quality of life. Source: The King's Fund https://www.kingsfund.org.uk/audio-video/how-new-nhs-structured. Reprinted by permission

Waiting times continue to increase and quality of care is not consistent with more money needed if the NHS is to survive.

At the same time, however, the NHS is also facing staff shortages that could worsen if it becomes more difficult to recruit and retain staff from the European Union (Ham, 2017; McKenna, 2017) following Brexit. In the run-up to the June 2017 election, public opinion was divided about whether the NHS should be able to maintain standards of care within its current budget or whether additional public spending will be needed.

Scope of NHS Responsibilities

In 2018, the NHS will be 70 years old. It is the world's fifth biggest employer after the United States Department of Defense, Walmart, and McDonald's (NHS Confederation, 2016). The NHS today employs more than 1.7 million staff who deal with one million patients every 36 h (NHS Confederation, 2016).

The NHS is the world's largest publicly funded health service and remains free at the point of use for all the UK residents. It received a budget of £437 million when it was launched in 1948, which would be approximately £15 billion in today's value (NHS England, 2016).

According to the King's Fund (2016), spending on the NHS will rise by £35 billion in cash terms between 2009/10 and 2020/21, a rise of 35 percent. However, much of this increase will be swallowed by rising prices and inflation absorbing £24 billion; leaving a real increase of only £11 billion. This represents a rise of 10% over 11 years, with an average annual increase of just 0.9% (King's Fund, 2016) (Figs. 19.2 and 19.3).

The strain on the NHS is reaching critical levels—the population is aging, needs are changing due to demographics, and people are demanding more from their healthcare. Change is the only way forward and the blueprint for the NHS, the *Five-Year Forward View*, is described in the next section.

The Five-Year Forward View (FYFV)

The *Five-Year Forward View* (FYFV) was launched in 2014 by the NHS Chief Executive to improve outcomes, public satisfaction, and quality of care by 2020. It was also intended to achieve £22 billion in efficiency savings. The FYFV is essentially a plan of what the NHS will need to do to if it is to be able to restore itself to financial balance, and it includes key short-term priorities and practical actions for national service improvements (NHS England, 2017a).

For example, some of the pressure on Accident and Emergency departments and increasing demand on the services they provide across the country could potentially be better resolved closer to home if supported by a more accessible and better-resourced

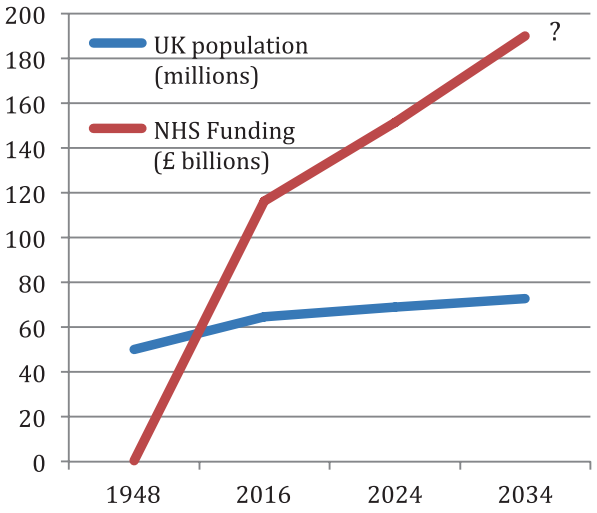

Fig. 19.2 Growth in NHS spending since 1948. Source: Author, based on data from The NHS In England (https://www.nhs.uk/nhsengland/thenhs/about/pages/overview.aspx) and the King's Fund (https://www.kingsfund.org.uk/audio-video/how-does-nhs-in-england-work)

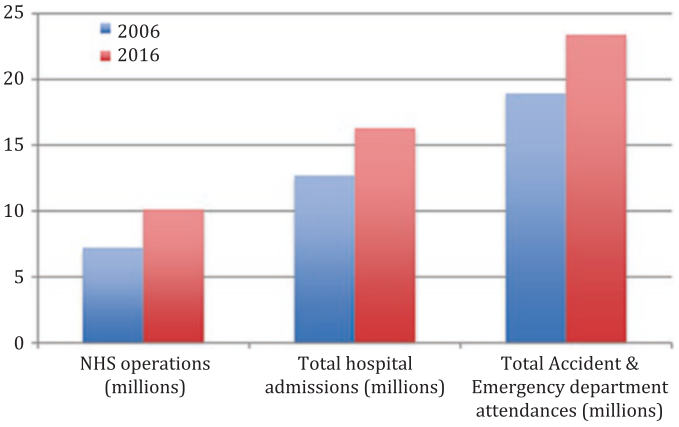

Fig. 19.3 NHS facts and figures. Source: NHS statistics, facts, and figures. NHS Confederation (http://www.nhsconfed.org/resources/key-statistics-on-the-nhs)

general practice, allowing patients to see their GP (general practitioner) when they need to.

Better care for cancer and mental health are also included as core areas of focus. Earlier diagnosis, increased treatment capacity, improved care coordination, and increased engagement with cancer patients will be embedded in the NHS accountability framework and will not only help more people survive cancer but will greatly improve the care experience (Cancer Research UK, 2015). An independent Mental Health Taskforce commissioned by Simon Stevens placed a strong emphasis on parity of mental and physical health; the importance of social care, employment, and housing; more timely access to care close to home; and increased investment to

improve access to care when and where it is needed rather than waiting until a personal crisis (Mental Health Taskforce to the NHS in England, 2016).

The National Information Board (NIB)

Better use of information and communications technology accelerates and improves the flow of health information among clinical providers (caring professionals), patients, researchers, and citizens, to their collective benefit. The National Information Board (NIB), originally chaired by Tim Kelsey, National Information Director at NHS England from 2012 to 2015, was established to bring together a variety of stakeholders to develop strategic priorities for health data and information technology in health and health care. It has featured members from NHS England, NHS Digital (then known as the Health and Social Care Information Centre), the Care Quality Commission (inspector and regulator of health and social care in England; established in 2009), NICE (National Institute for Health and Care Excellence), MHRA (Medicines and Healthcare Products Regulatory Agency), and the Department of Health.

Towards the end of 2014, NIB (2014) published *Personalised Health and Care 2020*, which included a framework for full citizen access to their records; transparency of outcomes and value of services; comparative information on treatments to increase effectiveness, efficiency, and value; workforce training in new technologies; and an environment that promotes innovation.

In the spring of 2017, the NIB Strategic Clinical Relevance Group released a set of clinical requirements for information and digital technologies that are intended to support the previous report and ensure that clinical priorities are met. These requirements represent closely integrated development of clinical and policy priorities by a multi-stakeholder effort.

Sustainability and Transformation Plans (STPs)

New ways of working are paramount to enabling the UK's much-loved NHS to continue to help and serve in the manner it has proudly done over the last 69 years. As such, more and more partnerships are growing between providers and commissioners (payers) as they begin to further integrate services and funding by working more effectively together to improve health and care in their local area and embrace the challenges ahead.

These partnerships now cover 44 areas of England and have translated into Sustainability and Transformation Plans (STPs), published by NHS England in 2016. These plans are intended to bring communities together and will to ensure that NHS organizations work collaboratively. The 44 STPs clearly state how improvements will be made and the combined financial savings achieved will be able to improve population health by tailoring plans to leverage and coordinate local

leadership, resources, and community engagement. As of July 2017, there is now a dashboard to assess progress against the plans.

Despite this brief history of the NHS and description of some of the current issues affecting the health service in England, perhaps the most important aspect of the FYFV from the point of view of this book is the NHS leadership's realization that it needs to fully exploit the potential of technology and accelerate innovation and what it can offer NHS. In short, better use of digital technology across the NHS as a whole would greatly benefit patients, providers, commissioners, and local authorities.

In addition, it is intended that the NHS more seamlessly share information across care settings and in different geographical locations so that wherever and whenever a patient chooses to access a desired health service all necessary information is instantly available for the clinician—to enable the best interaction possible, ensure efficiency, and achieve the desired outcomes for the patient. If digital technology is being optimized, then this would also allow the clinician to order any diagnostic tests, view these results, refer to another specialist in a different location, access medical records, and book another appointment either in person or remotely (if necessary); and all via a single sign-on. This can only be achieved with the right infrastructure in place and if the right workforce training investments are made.

Digital technology would also ensure a lasting legacy for the NHS—greater collaboration among specialist clinicians or providers could become routine rather than rare to save lives; information and resources could be more easily shared across health settings to streamline services and make them more efficient. And, patients themselves could more proactively manage their own healthcare to ease pressure on the NHS and safeguard its future for decades to come.

The Information Revolution

The *Five-Year Forward View* ably lays down the foundation for the NHS to better incorporate the use of digital technology in its continuing quest to improve patient care and experience. The NHS has had to adapt to peoples' expectations and their ability at accessing information via their smartphones or tablets whenever they need. This high-tech need has become apparent over a number of years but has now sped up thanks to the FYFV. Digital technology is now benefitting the NHS more widely and in turn has "simplified patient access to care, in the most appropriate location, while supporting people in managing their own health" (NHS England, 2017b).

As a patient in the NHS today, it should be entirely possible that you can access health services by phone or online whenever you need to. You might be able to have a consultation with your GP on the phone or via a *Skype* web-call. You might choose to book your appointment online instead and order any repeat medication prescriptions at the same time for collection at a convenient pharmacy; or even have them delivered to your front door. You could also access and read your summary care record.

However, while perhaps this may be possible in a city like London, it may not be if you live in rural Yorkshire. The FYFV view seeks to address this geographic discrepancy and "over the next two years the NHS will make very significant steps towards increasing how its services can be accessed online, while remembering that healthcare is about people and that many patients want and need the reassurance of a real person to talk to face-to-face" (NHS England, 2017b).

NHS Choices is a free to use and easily accessible healthcare website allowing visitors to find out more about common health conditions and illnesses, where to access health services in their area, an overview of hospital providers and their performance; as well as searching for a specialist, the latest health news, and advice for living well. Launched in 2007, by 2016 there were more than 1.5 million visits per day and over 550 million through the year. As of February 2017, 10.4 million people are registered for online services, with 1.9 million repeat prescriptions ordered online, 1.1 million appointments managed online, and one million views of patient records in the same time period" (NHS England, 2017b). It is hoped that by September 2017, *NHS Choices* will become *NHS.UK* to offer an improved patient experience that includes online scheduling and access to personal health records (NHS England, 2017b).

As of May 2017, the NHS is testing *NHS apps*, a digital apps library ready for launch later in 2017, with an initial focus on mental health and diabetes. These are two complex conditions where patients could benefit significantly from better integration of mental, physical, and social care. Mental illness is estimated to cost the UK economy as much as £100 billion a year in terms of healthcare, lost jobs, unemployment benefits, homelessness support, and police time (Johnson, 2016). An estimated £14 billion is spent a year on treating diabetes and its complications, with the cost of treating complications representing the much higher cost. The prevalence of diabetes is estimated to rise to four million by 2025 (Diabetes.co.uk, 2017).

Apps to be included in the new eLibrary will be one of three categories:

1. *NHS approved* will have a published evidence base and demonstrate they can help a person manage and improve their health;
2. *NHS connected* will "have been tested and approved for connection to NHS systems, allowing you to download information from NHS systems in the app;" and
3. *Health apps*, which will be a directory of other health applications you may choose to use (NHS Choices beta site, 2017).

As you can see, the NHS is well on its way to becoming a highly connected and digital health system, and so it was deemed appropriate to conduct a survey to assess and score the current state of digital technology across acute, community, and mental health providers in England. The first Digital Maturity Assessment (DMA) was conducted by NHS England towards the end of 2015 with the first results published on *MyNHS* in April 2016.

Because the adoption of digital technology has been much slower in secondary care than in primary care, the NHS wanted to see what the levels of adoption were for its 242 acute, community, and mental health providers and what will need to be done by 2020 if the *Five-Year Forward View* is to be realized.

The Wachter Review

In addition to the voluntary direct reporting by secondary care providers through the DMA, an independent interdisciplinary report was commissioned by Secretary of State for Health Sir Jeremy Hunt to advise the Department of Health and NHS England on progress towards digitizing the NHS. The National Advisory Group on Health IT in England, chaired by Robert Wachter, Professor and Interim Chairman of the Department of Medicine at the University of California, San Francisco, included experts from the UK, the USA, Europe, and Australia. The Group met with individuals and stakeholder groups, heard presentations, and reviewed a variety of materials to derive a series of principles and recommendations about implementation (Gov.UK, 2016).

In the fall of 2016, the Group released a report that came to be known as the *Wachter Review*. Its fundamental principles focused on the importance of staged implementation, user-centered design, and designing for interoperability from the start to promote clinical care, innovation, and research, among other goals. The recommendations highlighted the importance of a national chief clinical information officer (CCIO), a trained workforce, and linkage of national funding to a viable local improvement plan that reflects local resources and was locally developed (Gov.UK, 2016). These recommendations helped inform the latest update of the FYFV, published in April 2017, and its approach to digitizing the NHS (NHS England, 2017b).

The *Wachter Review* based its recommendations on a thorough review of previous NHS Health IT initiatives as well as initiatives in the USA, Australia, and Denmark. The Review was critical of the controversial National Program for IT (NPfIT), which had been launched in 2002 with an original estimated cost of £6.4 billion. Its budget however had swollen to nearly £10 billion by the time it was finally decided to abandon the program in 2011. Too much centralization and not enough engagement were cited as the key reasons behind its failure. The *Wachter Review* was careful to highlight this finding to the Department of Health and NHS England and its principles and recommendations were intended to ensure that NHS did not try to accomplish too much too fast, but instead recognized that technical and adaptive changes are multifaceted and take time (Gov.UK, 2016).

The *Wachter Review* recognizes that the better use of digital technology in the NHS will enable better health of the population and better healthcare, at a lower cost. Observers of the NHS note that while there is a keenness for secondary care to catch up with General Practice, now largely digitized after beginning in the 1980s, it is sensible to allow secondary care to adapt deliberately over time.

Lastly, the *Review* urges that the NHS' digital strategy "should involve a thoughtful blend of funding and resources to help defray that cost of IT purchases and implementation, resources for infrastructure, support for leadership and informatics training as well as support for education of leaders, front-line providers, trainees and clinician- and non-clinician informaticians" (NHS England, 2017b). The *Wachter Review* is clear to state that a phased approach is necessary and 2023 is

more realistic for the NHS to achieve sustainable digitization. At this writing, it appears that the £4.2 billion originally granted by the Treasury will fall short.

A Digital NHS: King's Fund Report

The King's Fund, an independent charity working to improve health and healthcare in England, published a report (Honeyman, Dunn, & McKenna, 2016) to coincide with the release of the *Wachter Review*. The King's Fund report sought to put the *Review* in context for local leaders developing implementation plans as well as provide an independent analysis of previous digital reforms and present data about the current state of interoperability and adoption of electronic health records.

The King's Fund report that authors agree with the Wachter *Review* that better digital technology can transform the NHS by offering more efficient services for both patient and clinician as well as better, faster, and more reliable communication and information sharing. The King's Fund report also notes that 2020 is too optimistic to reach all of the digital technology goals and supports the year 2023 as a more credible milestone.

In addition, the King's Fund report reinforces that secondary care so far has lagged behind primary care in effective digitization, and it is for this reason that the Digital Maturity Assessment (DMA) is so important. For the first time, the DMA will allow NHS England to understand the current variation in adoption of digital technology and how progress can be carefully monitored over the coming years (to 2023).

Lastly, the King's Fund report confirms that a fully digital NHS can only be realized with the full engagement and participation of staff at all levels of each organization, and the systematic coordination of relevant training and education of administrative and clinical staff.

What would digitization actually mean for the NHS at a local level? Well, via the use of their smart phone or tablet, patients' would be much more proactive in their own health with immediate access to medical information, treatment plans, referrals, prescriptions, and their healthcare team when they need it; and clinicians themselves would be able to access health records with ease and security, order diagnostic tests at the push of a button, view tests results instantly, and even offer advice to patients remotely. Digitization would save the NHS money in lost time and offer faster access to better and safer care (Fig. 19.4).

The Digital Maturity Assessment

The Digital Maturity Assessment (DMA) is a tool used by NHS England to benchmark digital technology in England and capture progress over time—to demonstrate that NHS investment in digital technology is helping to achieve the desired patient outcomes and offering the intended value for money across the health service. The

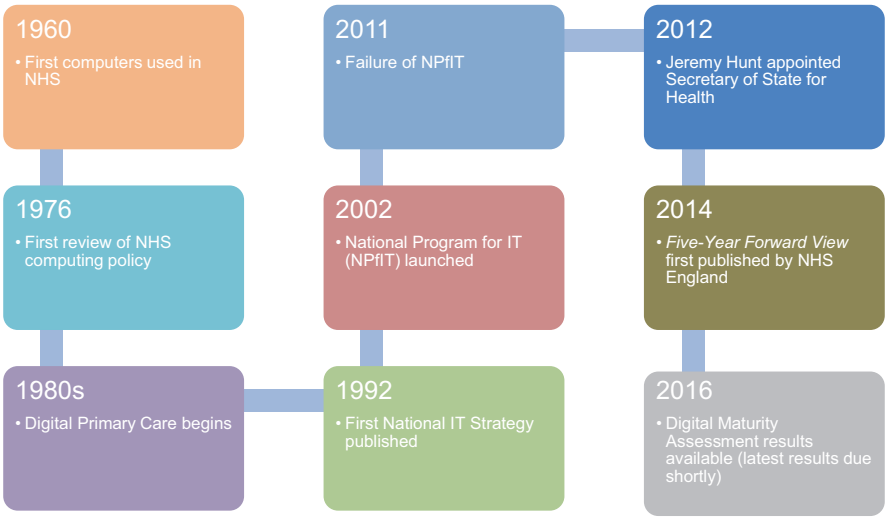

Fig. 19.4 Brief timeline of NHS digital milestones. Source: Author, based on the Wachter Review (Gov.UK, 2016) and the King's Fund NHS Digital Review (The King's Fund, 2016)

DMA is still in its infancy and there will remain a strong challenge for all providers of acute, mental health, and community providers to become paper-free by 2020.

Over the past few decades, government funding has supported adoption of electronic health record systems (EHRs) in GP practices, which are used exclusively for clinical purposes and not for documentation to justify billing, as they are in the USA. These systems were designed in close collaboration with GPs and as a result, EHR adoption among GPs (primary care) is nearly universal. However, much of the information that comes from secondary care (e.g., hospitals and specialists) remains paper-based and must be scanned into the record (Gov.UK, 2016).

The Digital Maturity Assessment (DMA) seeks to address the technology challenge secondary care is facing by collecting information on current digital ability and level of adoption across the NHS. The DMA provides a baseline and benchmark progress in order to enable a more sustainable digital infrastructure, which in turn will lead to better clinical outcomes, better patient experience, and better value for money—echoing the NIB's *Personalised Health and Care 2020* and Simon Stevens' *Five-Year Forward View.*

Before building the DMA, NHS England had examined the Canadian Electronic Medical Record (EMR) Adoption and Maturity Model, which has been used to demonstrate both clinical value and program investment. NHS England included the Healthcare IT database from the American Hospital Association, which monitors the level of adoption of electronic medical records across 3500 hospitals in the USA, in its research.

The EMR Adoption Model (EMRAM) from HIMSS Analytics Europe was also considered. EMRAM is an eight-stage model to support the use of digital technology and is recognized by healthcare organizations around the world. NHS England

ultimately partnered with UCLPartners (UCLP) in London to help design and implement the DMA. UCLP has a strong informatics program, led by Dr. Cathy Kelly as Chief Information Officer, that is intended to transform services and improve quality of care.

The core objectives of the DMA during its first year were to:

1. *Identify key strength and gaps* in providers' ability to operate paper-free at the point of care;
2. *Support internal planning, prioritization, and investment decisions* within providers towards operating paper-free;
3. *Support planning and prioritizing of investment decisions* within commissioner-led footprints to move local health and care economies towards operating paper-free;
4. *Provide a means of baselining/benchmarking nationally* the current ability of providers to operate paper-free; and
5. *Identify capacity and capability gaps* in local health and care economies to transform services and operate paper-free.

These objectives will likely evolve as the DMA itself evolves over the coming years to track the advances in digital capability across the NHS.

The DMA is a self-assessment survey comprising of 133 questions grouped into three sections: (1) Readiness—are providers set up effectively to deliver paper-free at the point of care; (2) Capabilities—do providers have the necessary digital capabilities they need to deliver paper-free at the point of care, and (3) Infrastructure—is the technology actually in place to deliver paper-free at the point of care.

The DMA is simple and easy to use with each question requiring an answer from a drop-down pick list or free text. Overall scores are based on how well providers are set up and use digital technology and how they share information across their organization and outside. The scores for 2015–2016 are available on *MyNHS*. (The latest scores for 2016–2017 are due later in 2017.)

The "readiness" section of the DMA included five subsections on: (1) strategic alignment, (2) leadership, (3) resourcing, (4) governance, and (5) information governance. Specifically, the questions here focused on whether or not the provider had a clearly defined and Board-level digital strategy to support clinical and corporate objectives across the organization; whether there is strong leadership from a dedicated Clinical Information Officer or Chief Clinical Information Officer to deliver this strategy; and whether there are sufficient resources in place to support and transform services.

"Capabilities" included separate questions on:

(1) *Records, assessments, and plans*—is patient information available digitally to all health and care professionals who need it?
(2) *Medicines management*—is prescribing, dispensing, and administration managed digitally?
(3) *Orders*—are orders captured, transmitted, and fulfilled digitally?

(4) *Transfers and communications*—does digital information follow the patient across care settings and is this information shared?
(5) *Decision support*—do health and care professionals receive active support from digital systems to improve service delivery?
(6) *Remote and assistive care*—can health and care professionals monitor and care for patients remotely?
(7) *Asset and resource optimization*—are digital systems in place to ensure vital assets and resources are used effectively and efficiently?

The last section of the DMA is on "infrastructure" and this included questions on:

(1) *WiFi*—is it available to staff and patients in all buildings on all sites?
(2) *Business continuity*—recovery processes are clearly documented and roles agreed.
(3) *Mobile*—health and care professionals are equipped with a mobile device (smart tablet) at the point of care.
(4) *System resilience*—business critical systems are supported by robust IT infrastructure.
(5) *Virtual desktop*—clinical applications can be accessed this way.
(6) *Single sign on*—health and care professionals have a single sign on for all the clinical applications and computer programs they access.

Buy-in to the DMA was crucial at its launch, and so all acute, community, and mental health providers who were to be assessed became part of the process to ensure that ideas were shared, feedback sought, and amendments made to ensure maximum success after launch. Nationwide forums and workshops were held to share details with stakeholders so that questions could be asked and any concerns put to rest. Dedicated contacted details were shared so that any issues could be raised and dealt with accordingly in advance.

The DMA is not mandatory and providers only need volunteer their information if they choose. What is interesting is that every provider who took part completed their assessment within the three months the survey was available to them. NHS England received a full complement of responses from every organization contacted. Each provider had been asked to identify a lead nominee to champion the DMA in their organization and they all personally received a letter from Tim Kelsey on behalf of Simon Stevens urging them to complete the self-assessment if at all possible.

To validate responses, ten providers were selected at random to undergo a quality assurance site visit. These included verification of documents and interviews with Board-level and customer-facing staff to ensure credibility, integrity, and honesty.

So what next for the DMA? The results from 2017 are expected later in 2018 and a minimum dataset or national standards of digital technology for secondary care will also be expected to reduce variation and ensure interoperability across the NHS by 2023 (Fig. 19.5).

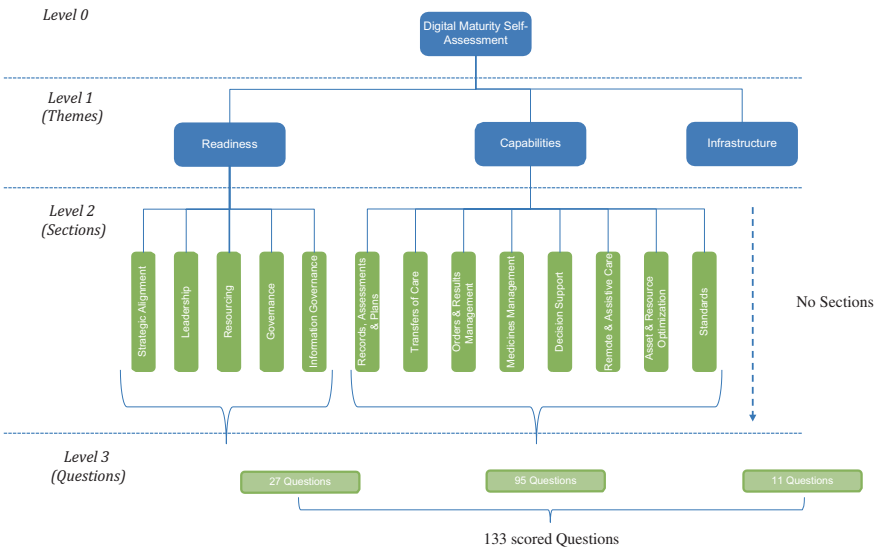

Fig. 19.5 Digital maturity self-assessment: data model/structure. Source: NHS England (2016). https://www.england.nhs.uk/digitaltechnology/info-revolution/maturity-index/

Future Opportunities

As a way forward, NHS England has recently announced 16 "Global Digital Exemplars," all carefully selected based on their Digital Maturity Assessment results. These acute care providers currently have the most advanced digital technology in the NHS and will receive £10 million in additional funding. They are expected to partner internationally to "develop a blueprint that can be deployed to other hospitals, reducing the time and cost for further adoption" (NHS England, 2017b).

It is also anticipated that a further 20 organizations will become "National Exemplars" and receive £5 million in funding and encouragement from the new NHS Digital Academy when it is operational in the latter part of 2017. A direct result of the *Wachter Review,* the NHS Digital Academy will train the next generation of Chief Information Officers and Chief Clinical Information Officers to maximize their skillsets so that the use of digital technology becomes fully aligned to the success of the NHS.

It is possible that digital maturity will be incorporated into the annual inspection of health and care organizations by the Care Quality Commission (CQC). Each year, the CQC selects a number of providers to assess their care according to their five key lines of enquiry (safe, effective, caring, responsive, and well-led); and rate the organization as "outstanding, good, requires improvement, or inadequate." Effective use of digital technology is certainly something the CQC should consider as it embarks on its latest inspection regime.

Cancer Waiting Times could also benefit from improved digital technology. At present, all NHS patients with a suspected cancer referred by their GPs need to be seen within 14 days. A definitive diagnosis is then expected in 31 days (although this will reduce to 28 days from March 2018) and they will receive their first treatment within 62 days. The NHS is struggling to meet the 62-day target nationally and better use of digital technology could make a significant difference.

If patients were electronically tracked from the moment of referral and throughout their courses of treatment, then it would be much easier to ensure appropriate access; as well as preventing them from becoming "lost" in the system especially if they are transferred to a different provider. This does already happen in some places, but not everywhere, and so there will be some organizations that could benefit from the new (global) and national digital exemplars. If the exemplars are currently getting it right, then they will be expected to share with others. In fact, patients should also be able to track themselves via their "NHS connective" smart phone and automatically alert their healthcare professional if their treatment is delayed.

Local Digital Roadmaps (LDRs) will detail the steps needed for organizations to collectively achieve in becoming paper-free and will include strategic and operational objectives to align with the requirements of the *Five-Year Forward View.* There are currently 65 LDRs which should synchronize with 44 Sustainability and Transformation Plans (STPs), which detail how health and care will be improved locally and also save the NHS money in the longer-term.

It is highly possible that the number of STPs will be reduced as providers and clinical commissioning groups work together more collaboratively than ever before and that a new, high quality, and sustainable NHS will emerge.

Summary and Closing

The NHS has an incredible opportunity in its sights. After the failure of NPfIT in 2011, the digital agenda in secondary care has been reinvigorated and brought to life by the *Five-Year Forward View*: admirable in its willingness in seeking to provide a long-lasting NHS with quality services and patient care; and admirable in recognizing that technology and innovation are central to the future success of the NHS.

The road ahead will not be easy and the original end date of 2020 now seems more than a little optimistic to be able to fully implement a digitally interoperable health and care system, particularly as the NHS faces unprecedented financial pressure. It is the now-in-place Sustainability and Transformation Plans that should start to ease this pressure, as long as organizations work in collaboration with each other and not in isolation.

The Digital Maturity Assessment has enabled an accurate picture of the state of digital technology across the NHS and for progress to be tracked as the NHS moves towards 2020 and beyond. It is heartening to see effective digitization being embraced by secondary care. A recent scan of the *Operational Plan 2017–2018* for Guy's and St Thomas' NHS Foundation Trust (a large teaching hospital in south

London with a £1.3 billion turnover per year and 2.3 million patient contacts in 2015–2016) states that they are "developing a program of work that uses digital technology to improve how we communicate and support new ways of working that will benefit patients and staff" (Guy's and St. Thomas NHS Foundation Trust, 2016).

The Trust Board at University College London Hospitals NHS Foundation Trust (UCLH) announced this July its decision to partner with the US supplier *Epic* to deliver a new electronic patient record. The Trust said "the key to success will be the close involvement of patients, clinicians and researchers so that everyone benefits quickly when we go live in 2019" (UCLH, 2017).

The *Wachter Review* concludes that if the NHS can "balance limited centralization with an emphasis on local and regional control, build and empower the appropriate workforce, create a timeline that stages implementation and learns from the past, this effort will create the infrastructure to provide safe, satisfying and affordable healthcare" (Gov.UK, 2016).

Over the last seven decades, the NHS has become engrained in the national consciousness—the UK would be unimaginable without it. With the dedicated focus and due diligence it deserves, the best years of the NHS are still yet to come.

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Part V
Conclusion

Chapter 20
Back to the Future: Emerging Technology, Social, and Cultural Trends Affecting Consumer Informatics

Margo Edmunds, Christopher Hass, and Erin Holve

Introduction

Nearly 20 years ago, in the book *High Tech/High Touch*, John Naisbitt observed that the two biggest markets in the USA are consumer technology and escape from consumer technology (Naisbitt, Naisbitt, & Philips, 1999). The global digital health market is projected to reach $189 billion by 2025 (Research and Markets (2017), embedded within an overall $6.5 trillion healthcare industry that is projected to grow to $8.5 trillion by 2030 (World Economic Forum, 2017).

At the other end of the spectrum, we have the global travel and tourism industry, worth $2.3 trillion US dollars in 2016 (Statista, n.d.); a global spa industry worth $94 billion; a melding of fashion and sport with fashion and fitness bloggers, e.g., a jewelry line for Fitbit (Fitbit.com, n.d.); wearable devices embedded in sports apparel, and many other examples. We also have a growing national discussion about health equity happening in several policy and research circles, in which a fundamental right to access digital technology to help maintain health is assumed but by no means assured (IOM/NAM, 2009; National Academies of Sciences, Engineering, and Medicine, 2016).

If we had to choose, we would say that the four most important drivers for consumer informatics today are:

M. Edmunds (✉)
AcademyHealth, Washington, DC, USA

C. Hass
Boston, MA, USA
e-mail: chris@createwww.com

E. Holve
Department of Health Care Finance, Government of the District of Columbia, Washington, DC, USA

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1. The rapid pace of innovation within the digital technology sector, which has created numerous new possibilities for consumer health IT and raised many questions about its integration with clinical information;
2. The person-centered provisions of the Affordable Care Act (ACA), which promote consumers' access to their personal health information and support provider–patient partnerships at the point of care;
3. The emphasis on value-based payment for health outcomes, which shifts incentives away from fee-for-service payment models that create inefficiencies and fragment care; and,
4. The shifting demographics of the population, increasing the importance of ensuring that analog and digital systems are understandable, accessible, and effective for achieving consumer, clinical, and population health objectives.

All four drivers complement and support one another, yet none are exactly quantifiable. Consequently, this chapter reflects our experiences over the past year conceptualizing, commissioning, and curating the development of the chapters in *Consumer Informatics and Digital Health* from both policy and pragmatic perspectives. We sought to take into account the long-term impact of technological changes on systems and organizational cultures, and to recognize and appreciate the complexity of stakeholder interactions in the health and health care ecosystems, while trying to maintain a focus on consumer impact and engagement.

In our view, despite major challenges and unprecedented changes to the national policy agenda since it was enacted, the passage of the ACA in 2010 set in motion some significant and potentially enduring changes to value-based purchasing and delivery of person-centered healthcare in the USA. The incentivized focus is gradually shifting towards paying for value rather than volume of services. For example, significant policy and procedure changes now pay care providers not for the individual procedures they greenlight, but for their patients' health outcomes from a bundle of services that can include consumer-facing technologies for remote monitoring of health status (Abrams et al., 2015; Holve, 2019).

At the same time that the ACA payment and delivery system reforms are well underway, we are also in the beginning stages of the era of "personalized" or "precision" medicine, with tailored interventions that custom fit medical products and treatment strategies to individual characteristics, needs, and preferences (National Research Council, 2012). This direction was boosted by funding from the 21st Century Cures Act, passed with bipartisan support in December 2016.

The success of precision medicine will depend on the ability to share, integrate, and analyze a variety of data types (e.g., laboratory, imaging, genomics, and clinical notes) in a trusted, collaborative, human-usable environment. For this reason, 21st Century Cures includes several provisions intended to improve interoperability, exchange of electronic health information, and patient access to data that will take several years to fully roll out (Landi, 2016). As of February 2018, the Trusted Exchange Framework and Common Agreement (TEFCA), an important step under the Cures Act, has been released for public comment.

It is too soon to assess the impact of new legislation and policy, but we take the long view. Democratization of health care information; purchasing, payment, and delivery system reform; the intention and ability to tailor health interventions to individual, clinical, cultural, and population health needs; and an increasing recognition of the importance of user experiences are critical steps towards achieving our shared goal of improving individual and population health. Value-based innovation is the name of the game to help us get there.

Opportunities and Challenges

The consumer health informatics ecosystem is highly complex, with many opportunities and challenges that engage and impact different stakeholders in different ways. However, we found some cross-cutting themes across settings and stakeholder groups as they engage with each other that deserve further discussion and exploration. These include recognizing the importance of patient autonomy and the value of the consumer voice; understanding and building systems of care that support personalized care; paying for new models of care that integrate technology as well as personal and environmental risks; navigating the management of electronic records to encompass a broader view of health; and building a culture of trust that recognizes personal and organizational risk and perception of risk.

Recognizing the Value of the Consumer Voice

The Affordable Care Act (ACA) contained many provisions to encourage person-centered care, which is frequently described as "patient-centered care." While many terms and definitions have been used over the years, most center on the shift from provider-centered services to a more equitable partnership that values the needs and preferences of those who receive services (e.g., patients, individuals, or consumers). Among other things, it can mean that consumers can control the amount, duration, and scope of services; choose their providers; and be reasonably well supported in their expectations that their cultural, linguistic, and other social and environmental needs will be addressed.

Although the absence of the patient voice in the design of the US healthcare delivery system has received more attention of late, there are many practical strategies to enhance shared decision-making, communication, and other systems characteristics that matter most to patients (Bechtel & Ness, 2010). Despite ample evidence of consumers' interest in engaging more actively with their providers (Edmunds, 2019), it is still more often the case that providers develop systems and then "educate" consumers and patients in how to use them (Bechtel & Ness, 2010).

Concurrently, technology has become embedded in several parts of the health care system, including diagnostics, treatment, communications, and analytics (Baitman & Karpay 2017; Kish, 2017). Where consumer-facing technology is concerned, we know that many consumers are interested in having online access to their clinical providers and their own personal health information. We also know that person-centered design principles are vital to ensuring that health information is tailored, or personalized, while meeting complex legal and security requirements. In sum, to achieve person-centered care, one size does *not* fit all.

Pediatric telehealth is one area in which rapid innovation is making it easier for parents to care for sick infants and children around the clock, both through their regular providers and through access to telehealth services (Raskas, Gali, Schinasi, & Vyas, 2019). Telehealth does not replace face-to-face visits, but it makes care more accessible by reducing travel time and burden, and has been shown to reduce use of emergency departments, and caregivers' time away from work. Perhaps the most important benefit is that needed treatments can begin sooner than they might otherwise if travel were involved, which is good for both patients and caregivers alike.

Consumers want technology to work for them, and want to reduce the burden of being sick—not add to it. They want the providers in their ecosystem of care to be connected electronically so they can have seamless sharing of information on their behalf, rather than having to physically transport imaging files and paper record from office to office (Beckjord, Ahern, & Hesse, 2019). Shared care plans (SCPs) are another approach, in which patients, families, and the health care team work together to develop a comprehensive and evidence-based plan for care that can be accessed by all of them electronically (Kim, Jalil, & Ngo, 2019).

Consumer Technology and User-Centered Design

According to Dr. Eric Topol, arguably the most influential futurist in medicine, democratization and equal quality of information among stakeholders will upend health care for patients and clinicians, with the smartphone at the hub of a "medical revolution with little devices." Dr. Topol likens this shift towards consumer health informatics to the invention of Gutenberg's printing press (Kish, 2017; Topol, 2015), which greatly increased the spread of knowledge to many more people.

Nearly nine out of ten adults in the USA use at least one online social network, across all age groups, demographic and economic levels, and roles in the healthcare system (i.e., patient, provider) (Bishop, 2019). The increasing consumer use of online platforms and leveling of access to consumer technology driven by smartphones has helped to create a new ecosystem of online communications between consumers and providers that somehow seems to have overcome concerns about emotional distance that were expressed before consumer technology became so familiar. Online communication is one way of democratizing health care by removing barriers to face-to-face communications and reducing the time constraints of 9–5 clinic hours.

While consumers may love their apps, providers don't know what to do with the deluge of data they generate. Particularly notable is that stand-alone health apps are rarely used by consumers. Of the more than 80,000 health-related apps on the Apple App Store, the vast majority are never downloaded, or are downloaded and not used (Robbins, Krebs, Jagannathan, Jean-Louis, & Duncan, 2017). This happens for a number of reasons. Some applications are avoided or abandoned after initial use because they don't provide any useful consumer services, because they are difficult to use and/or lack an engaging user-interaction design, and primarily because their lasting value is all too often not properly grounded in best practices in motivational and behavioral change.

Gamification, or game-based learning, has caught the attention of many behavior change experts in academia, industry, and health to promote knowledge and learning through engagement with online tools (e.g., Seaborn & Fels, 2015; Kapp, 2014). Many health apps utilize "persuasive" techniques such as punitive messaging or "gamification" style leaderboards that publicize top scorers among a user group. They may have elaborate point earning systems offering external rewards that provide little longitudinal value to consumers, and "educational" content that provides focuses more on the dangers of unhealthy habits than the benefits of healthy habits. Broadly stated, persuasive techniques seek to inspire action through fear ("If you don't change your ways, you will have a bad health outcome"), or bribery ("floss your teeth every day for a month, and you could earn enough points to give you a discount or 'purchase' a product"). Techniques are largely short term, requiring repetition and intensity to sustain long-term impacts.

In contrast, motivational approaches seek to help users empower themselves (DiTommaso, 2019). Motivational techniques in application design first identify behaviors and practices that clinicians and healthcare professionals hope to engender in patients and consumers (healthy eating, routine exercise, smoking cessation, and medicinal adherence, among others). Next, cognitive design best practices (analog and digital) are employed for educating, informing, and inspiring application users to envision their "better" selves (e.g., Acharya & Whitney, 2018). This linkage helps to build bridges to that future through clinically responsible steps bolstered by interaction designs that are engaging, artful, informative and, most importantly, are directed towards a clear purpose.

From a design perspective, achieving success here involves cultivating and maintaining a focused and unbiased understanding of the patients and consumers for whom the application is ostensibly designed to be beneficial, not just a clinical presentation of intervention steps divorced from individuals' daily lives, including healthcare, cultural, economic, technological, familial support, and informational ecosystems. Too often, by focusing directly on consumers themselves, apps are not designed to be integrated into the consumers' electronic health record or other administrative systems that provide the basic logistical access to services patients want, such as scheduling or cancelling appointments, viewing lab results, or filling prescriptions. How can we expect patients to "take control" of their well-being if care systems continue to be institutionally siloed instead of part of individuals' digital, analog, and in-person health ecosystems?

Meeting the Organizational and Cultural Challenges of Person–Centered Care

Health systems are learning to listen to their patients and learn more about their care preferences through surveys, focus groups, and observation (Beckjord et al., 2019; Copeland, Wong, Jones, & Edmunds, 2019; Kim et al., 2019; Petersen, 2016; Petersen, 2019). Many are opening "innovation centers" to incubate new care processes, improve clinical workflows, and develop advanced data analytics capabilities to improve patient outcomes (e.g., Byers, 2017; https://www.healthcaredive.com/news/dive-awards-2017-healthcare-executive-rasu-shrestha/508894/).

An example is Sutter Health, where the Chief Innovation Officer and his team are redesigning physical spaces to make them more patient-, family-, and provider-friendly (https://news.sutterhealth.org/2015/10/21/sutter-health-welcomes-new-innovation-officer/). Along a similar vein, a team at the University of Michigan Institute for Healthcare Policy and Innovation has suggested adapting some airport systems and processes for hospitals (see Fig. 20.1).

Within health systems and provider organizations, Patient and Family Advisory Committees (PFAC) are becoming more common, and they have an increasing

Fig. 20.1 Source: Chopra V. Elements of airport process design that could be adopted by hospitals. © 2017 Vineet Chopra. Used with Permission. Adapted from Mullangi S, Ibrahim AM, Chopra V. Toward Patient-Centered Hospital Design: What Can Airports Teach Us? Ann Intern Med. 2017;167:48–49. Retrieved from "Toward Patient-Centered Hospital Design: What Can Airports Teach Us? http://bit.ly/2rBAXJJ #VisualAbstract"[Twitter post]. https://twitter.com/AnnalsofIM/status/869629720694059010. Posted May 30, 2017

prominence in decision-making. As a result of recommendations from PFACs across the country, approaches to technology such as Project Open Notes (in which clinical notes are shared directly with patients (Open Notes, n.d.)) have received more attention and had a greater likelihood of implementation beyond the early adopters such as Kaiser Permanente (e.g., AMA STEPS Forward https://www.stepsforward.org/modules/pfac; www.opennotes.org; Institute for Patient and Family Centered Care (n.d.) http://www.ipfcc.org/resources/storycorps.html).

Another cultural influencer is the Patient-Centered Outcomes Research Institute (PCORI), which was created by the ACA to support research guided by patients, caregivers, and the larger healthcare community. PCORI has a national patient engagement advisory panel and encourages its grantees to engage patients in local engagement advisory panels, providing direction and incentives for the patient voice to be included in comparative effectiveness research and patient-centered outcomes research (PCOR). The PCORI Ambassadors program has supported active engagement of consumer volunteers as research partners who also help to ensure the sharing and use of information from PCORI-funded research.

One of the newest and most promising cultural changes in organized medicine is the growing adoption of social media platforms to help disseminate research findings from peer-reviewed journals (Ibrahim, Lillemoe, Klingensmith, & Dimick, 2017). This distribution strategy makes the information much more accessible to consumers, media, and other members of the public as well as to clinical providers. Last year, the *Annals of Surgery* took dissemination a step farther and started using "visual abstracts" that translate the text from a traditional abstract into images that communicate faster using non-technical language and are more likely to be distributed online (Ibrahim et al., 2017).

Even more challenging than technology adoption in clinical culture, however, is shared decision-making, which was first proposed more than 20 years ago (Charles, Gafni, & Whelan, 1997). Nine out of 10 American adults say they want to participate as partners in decision-making about their medical treatments (Lynch, Perosino, & Slover, 2014), but these partnerships can challenge the dynamics of the embedded power relationships unless there is leadership by example and accountability at all levels of the organization (Edmunds, 2019). Shared decision-making is still considered a "work in progress" (Berwick, 2009; Tan & Goonawardene, 2017).

Incorporating Technology into New Care Models and Payment Reform

When it was passed, the Affordable Care Act (ACA) contained health insurance coverage expansion options, which have been the subject of much public debate. However, it also contained provisions to change the way health care is delivered and paid for, with the goals of reducing inefficiencies and costs as well as improving the patient experience. Payment reforms were introduced to shift from paying for volume to paying for value (Abrams et al., 2015; Holve, 2019), which encouraged alternative payment models including bundled payments. These considerations play

out for payors, providers, and patients in different ways, all of which seek to incorporate technology into new models of care in a thoughtful and sustainable way.

Because these models emphasize payment for outcomes rather than payment by service, they give providers financial incentives to integrate new modalities of care that leverage telehealth, smartphones, tablets, and other tools that consumers now see as part of their customary care. One of the big unanswered questions for purchasers and providers is how best to support utilization of new consumer health informatics tools as *modalities* of care, rather than simply creating a market for service.

In other words, successfully bending the cost curve necessitates a careful balance of incentives for innovation, and checks to mitigate concerns about waste, fraud, and abuse. One promising strategy to strike this balance is bundling the cost of technology into services that pay providers for achieving specific outcomes such as reducing the number of non-urgent ER visits, rather than simply creating new codes which can be billed under fee-for-service medicine. For example, a supervised preoperative exercise program before elective surgery was found to reduce postoperative cardiac, respiratory, and renal complications and shortened the length of hospital stay (Barakat, Shahin, Khan, McCollum, & Chetter, 2016).

Assuming payment models evolve and adapt to fully incorporate consumer informatics in the next few years, a related challenge is supporting providers' investments by adapting their clinical workflows so that technology is integrated seamlessly into care delivery (Unerti, Novak, Johnson, & Lorenzi, 2010). Examples range from implementing electronic health records and providing medication therapy management to reduce the likelihood of harmful drug interactions, to facilitating the use of remote patient monitoring of blood pressure and telehealth consultations with specialists to reduce unnecessary utilization of emergency rooms (Fig. 20.2).

Deciding where to place "bets" on technology is doubly challenging for providers because evidence is mixed or missing to determine which technologies are most effective at achieving better health outcomes and ideally, lowering costs (Tuckson, Edmunds, & Hodgkins, 2017). Funding programs such as CMS' State Innovation Model grants demonstrate that providers and researchers are making strides to evaluate the effectiveness of consumer informatics in their own practices and health systems, often as part of quality improvement or patient satisfaction assessments. As a result of CMS' programs, among other innovative initiatives, most providers now accept the need to adapt their clinical practices to new technology in order to provide person-centered care and be successful implementing VBP models. However, many providers report they are under-capitalized for transformation, particularly to support staff training and implementation of new technology, including workflow redesign.

In the USA, CMS has publicly acknowledged this need and has issued recent calls for comments on the areas in which the Federal government should continue to invest in innovation (https://innovation.cms.gov/initiatives/direction/). Like most questions of this type, there are no easy answers for Federal funders and regulators. Still, it is noteworthy that we have reached the point at which policymakers recognize that ongoing investment in technology and a technologically savvy workforce will be necessary if we are to truly transform health care delivery and deliver on the promise of person-centered care.

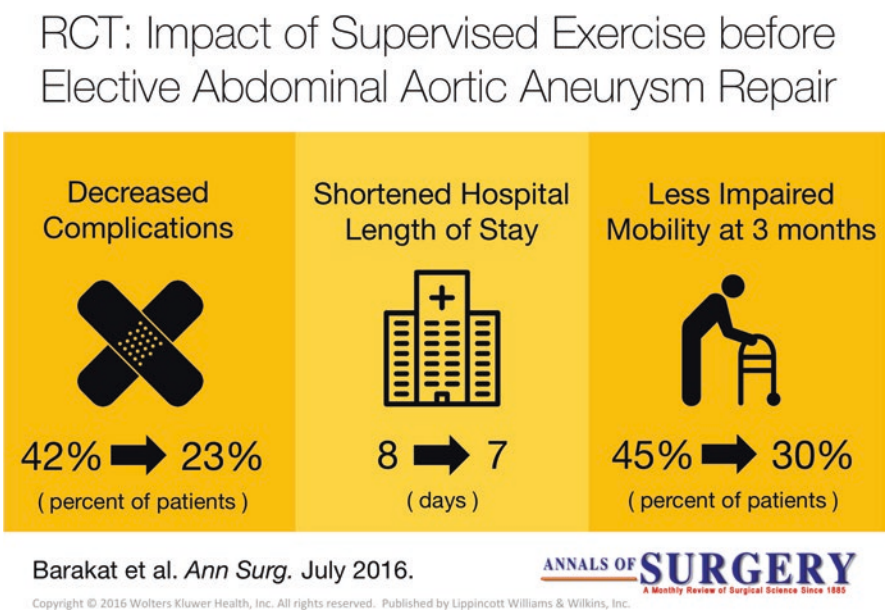

Fig. 20.2 Functional capacity predicts postoperative surgical outcomes. Source: Barakat et al. (2016). Used with permission

Moving Social and Environmental Risk Data into Electronic Health Records (EHRs)

One of the most deeply held principles of public health and community health is that individual health is determined by a complex combination of social, economic, environmental, and genetic factors. Evidence suggests that only about 10% of an individuals' health can be attributed to the health care system (McGinnis, Williams-Russo, & Knickman, 2002). The term "social determinants of health" is relatively new in health care, but it has caught on in policy and research circles, driven by a convergence of public and private sector interest in finding an increasing role for health care delivery systems in improving population health (Holve, 2019; Hripcsak, Forrest, Brennan, & Stead, 2015; Hull & Edmunds, 2019; Magnan, 2017; RWJF, 2017).

Even if they are open to the idea of addressing social determinants, most providers and health systems do not currently have access to the kinds of information that would allow them to make more informed clinical decisions. To address this gap, several national initiatives, such as the IOM Committee on Recommended Social and Behavioral Domains and Measures for Electronic Health Records (IOM, 2014) have spurred innovations in measuring social determinants and including the information in the electronic health record (EHR). Most of the IOM domains (e.g., education, race/ethnicity, financial resource strain, social connections, exposure to violence) address information that is only or primarily available from patients, then entered into the EHR by patients or staff.

Another approach, developed by a partnership involving the Robert Graham Center, OCHIN, and Health Landscape, and funded by the Patient-Centered Outcomes Research Institute (PCORI), has been testing the use of publicly available, structured data to develop "community vital signs" (Bazemore et al., 2015). The team has successfully integrated geocoded information from neighborhood geospatial maps into the EHRs of patients seen at community health centers. Once the community data are integrated with EHRs, there will be further study to determine how the data should be aggregated, displayed to clinicians, built into clinical decision support (CDS) tools, and used for community health planning and interventions.

In a closely aligned initiative, the National Association of Community Health Centers (NACHC) and partners developed the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE), which has 16 core measures that can help clinicians address patients' social determinants (National Association of Community Health Centers et al., 2016). PRAPARE templates are freely available for several EHRs, including those developed by eClinicalWorks, Epic, GE Centricity, and NextGen.

Similarly, CMS' Accountable Health Communities (https://innovation.cms.gov/initiatives/ahcm/) are engaged in assessing the value of implementing a structured assessment of social determinants (NAM: https://nam.edu/wp-content/uploads/2017/05/Standardized-Screening-for-Health-Related-Social-Needs-in-Clinical-Settings.pdf) in order to facilitate referrals from health care to human and social services. However, at this stage, the efforts to integrate health and social care are fragmented and lack a coordinated strategy, which may hamper efforts to measure and pay for care and social services that address social determinants.

Next steps for these projects include working with other stakeholders to develop plans for data curation and reuse. Aspirational goals include developing a structured core data set and determining the best way to promote the use of a standardized approach for clinicians and health systems to address social and economic risks. The sense of the community of practice working on these issues is that a collaborative, transparent, multi-sector process that focuses on sustainable collection and use of social determinants data is the best way to achieve lasting improvement.

As of late 2017, large EHR vendors such as Epic have begun advocating to change the terminology of "electronic health records" to "comprehensive health records" to more fully reflect the influence of social and environmental factors (Monegian, 2017). Cerner has also begun to offer a screening tool for social determinants in its inpatient EHR (https://www.healthdatamanagement.com/news/cerner-looks-to-integrate-social-determinants-of-health-into-workflow), and more such steps can be expected to meet the January 1, 2019 CMS requirement for its Comprehensive Primary Care Plus (CPC+) to address social and environmental factors impacting health.

Technical Challenges, Data Security, and Trust Frameworks

Mobile apps, consumer portals, and online tools offer new ways for consumers to be involved in managing their own health and in contributing to population health analytics and biomedical research. They also offer opportunities to generate an overwhelming amount of health data with varying levels of need for storage, curation, analysis, and integration with clinical data held within health systems.

Given the increasing number of sources of health data (e.g., clinical encounters, laboratory, imaging, genomic, patient-generated, social and behavioral, etc.); the increasing availability of personal health data to patients; the reuse of personal health information for quality improvement, research, population health planning, and public use; and the growth in distributed research networks across institutions, health care organizations are beginning to see the need to develop a data governance strategy that protects consumer privacy, maintains security, and ensures data quality (Holmes, 2016).

We are particularly interested in how health care organizations can promote consumers' access to their own health information while maintaining system and data security. Most patients and consumers encounter challenges when requesting and transferring their medical records, including high cost of duplication, lengthy delays, incomplete and inaccurate information, and formats that require manual entry into another health system's records (ONC, 2017). Fortunately, some new models of health care delivery have built-in secure technology infrastructure to promote data sharing with patients and with distributed research networks (Kim, Joseph, & Ohno-Machado, 2015).

There is ample evidence that patients are willing to share their information when they trust that their data will benefit others, will be used in the ways they are told it will be, and that steps will be taken to protect their privacy (Kim et al., 2015; McGraw & Leiter, 2013; Petersen, 2016; Weitzman, Kaci, & Mandl, 2010). Because there are varying levels of sensitivity based on the kinds of information that are being shared, it is highly advisable for health organizations to have a process that facilitates informed consent and allows patients to choose the types of data they are willing to share (Petersen, 2016; Wilbanks, 2019). The most sensitive data types involve certain diagnostic and genomic information, particularly where there is a social stigma (e.g., HIV/AIDS, serious mental illness, and reproductive health) or where there are fears that data might be shared with an employer or a commercial marketing firm without the person's consent.

In some cases, institutional review boards call for data governance policies and procedures to be developed within particular research efforts, but the sea change in the amount of data generated by the clinical and research enterprises will require changes in organizational culture to scale up and undertake multi-sector data sharing. It may include the addition of specialized personnel, such as patient advocacy representatives, privacy and security officers, regulatory experts, and others (Holmes, 2016).

Being deliberate and intentional about promoting consumers' access to their own information is vitally important. The Fair Information Practices Principles (FIPPs) are perhaps the most robust framework to balance data sharing and use practices with public trust (Baker, Kaye, & Terry, 2016). The principles were first published in the early 1970s and were incorporated in the Privacy Act of 1974, the HHS privacy and security framework, and the consumer privacy bill of rights as a code of conduct for Internet-based businesses.

But deliberation and good intentions are, unfortunately, not enough to protect consumers in the larger environment of security risks involving cybercrime, breaches, and the dark web (Sublett, 2017). On average, health care organizations spend $12 million a year related to cybercrime involving malicious code, insiders, hackers, phishing, malware, and stolen devices (Accenture, 2017). Consumers have good reason to fear breaches, which get widespread media coverage from industry and news sources. In 2017, the majority of healthcare providers experienced ransomware attacks, in which viruses keep them from accessing their data until a ransom was paid, and the largest data breaches were due to ransomware attacks, unauthorized server access, and computer viruses (Snell, 2017).

In June 2017, the Healthcare Industry Cybersecurity (HCIC) Task Force made several recommendations to increase security and resilience of medical devices and Health IT; improve industry readiness; develop workforce capacity; protect healthcare big data sets; and improve information sharing of industry threats, weaknesses, and mitigations (Health Care Industry Cybersecurity Task Force, 2017; Sublett, 2017). Successful implementation of the recommendations will require increased attention to and investment in preventive strategies, and a significant increase in collaboration and information-sharing above the current levels.

Strategies to Promote Technology Adoption in Health Care and Health

Predictive Analytics and Data–Driven Decisions

One of the reasons technology adoption is accelerating is the ability to generate valuable, real-time insights into patient care and population health management. Biomedical data are being produced and reproduced faster than at any time in history (Klenk, Payne, Shrestha, & Edmunds, 2019). The challenge is to be able to find the right data and the right context for making data-driven decisions that will be robust and sustainable given the new, complex, and evolving environment of value-based care (Holve, 2019).

Given the overwhelming amount of data most industries, organizations, and research teams are producing and curating, there is an urgent search for ways to mine, synthesize, and present information in a way that is more understandable and actionable for decision-makers. The much-discussed, emerging multidisciplinary field of data science combines methods from statistics, applied mathematics, computer

science, machine learning, biomedical informatics, and data visualization to develop fresh perspectives on new analytic tools. These include process simulation, text and voice analytics, social media analysis, and many others (Klenk et al., 2019; LaValle, Hopkins, Lesser, Shockley, & Kruschwitz, 2010).

According to an MIT-IBM global survey of nearly 3000 executive managers, supplemented by in-depth interviews, the greatest opportunity and most challenging way to increase the adoption rate for data analytics is to embed them into daily operations and workflow (Lavalle et al., 2010). Kaiser Permanente is one of the best-known exemplars following this path, using data analytics to focus resources on racial and ethnic disparities in health and access to care and many other areas of quality improvement (Copeland, Wong, Jones, & Edmunds, 2019).

Partners HealthCare Connected Health (Kvedar et al., 2017) is another example, where the focus is on digital health tools to improve health status and access through remote monitoring and virtual visits. And yet another model is UPMC, where investments in clinical tools, population health, business services, and consumerization are all part of its "living laboratory for innovation" (Baum, 2016). We're living in transformational times.

New training programs are emerging at a rapid pace to prepare the emerging workforce for the future by training them in systems thinking and cognitive sciences, thus helping them develop "sense making" and reasoning operations that will help them synthesize new sources of data. We posit that one of the best ways to help them pursue their training will be to establish multi-sector communities of practice connecting through virtual, open-science collaboration platforms (Edmunds et al., 2017b; Klenk et al., 2019; Payne, Lele, Johnson, & Holve, 2017).

Communities of Practice and Collaboration Platforms

Complex problems such as transforming health care and the research enterprise require coordinated attention and systems thinking from individuals with multiple perspectives, disciplines, and areas of expertise. This should not be controversial, but there are many historical, organizational, and cultural barriers to collaboration (Edmunds et al., 2017a; Edmunds et al., 2017b; Klenk et al., 2019). Without a technical infrastructure that supports information-sharing, collaboration, and open science approaches, it will be almost impossible to create the ecosystem that the complexity of our current challenges requires.

The futurist and science fiction novelist, Neal Stephenson, has observed that innovation cannot happen without accepting the risk of failure (Stephenson, 2011). Between the space exploration of the 1950s and 1960s and the Deepwater Horizon oil spill of 2010, Stephenson observes, the USA shifted towards innovations that control and manage risk rather than tackling increasingly complex scientific and technological problems. To promote a more expansive approach to innovation, Stephenson proposes a model of innovation in which real-world teams work on a mutual goals and function more like "a free and largely self-coordinated market of ideas" (Stephenson, 2011, p. 2).

Fortunately, there are many signs of transformational change. Multi-sector community coalitions all over the USA are addressing local conditions that increase social and economic risk factors and contribute to health disparities (AcademyHealth, 2017; Hull & Edmunds, 2019). Many use web-based virtual platforms that feature discussion threads, event calendars, repositories of toolkits and other practical information, and facilitate data-sharing across several organizations (AcademyHealth, 2017).

To help respond to a need for better information-sharing and knowledge integration in cancer research, a multidisciplinary team at the National Cancer Institute created the Team Science Toolkit with additional support from the Office for Behavioral and Social Sciences Research (OBSSR) (Vogel et al., 2013; National Cancer Institute, n.d.). Team science, also referred to as team-based research, has emerged as a way to reduce duplication of effort, highlight research gaps, disseminate best practices, accelerate evidence generation in scientific research, and improve reproducibility. The Team Science Toolkit is an online, user-generated collection of information and resources that integrates information from several disciplines, including public health, communications, management sciences, and psychology (NCI, n.d.).

Another model of collaboration is represented by the CIELO platform, which stands for Collaborative Informatics Environment for Learning on Health Outcomes (Payne, 2016; Payne et al., 2017). AcademyHealth's EDM Forum, supported by a cooperative agreement from the Agency for Healthcare Research and Quality (AHRQ), conducted a user-centered design process to determine the requirements for an open science platform for health research. The design and development of CIELO were thus tailored to an audience of experts who were working with electronic health data coming from electronic health records as well as patient-generated data. CIELO is currently supporting multi-site collaborations among distributed researchers funded by the National Institutes of Health.

Our observations about participating in—and curating—communities of practice with shared values are that the platforms and other tools help immeasurably to improve knowledge management. They also reinforce a sense of "teamness" that helps to support collaboration and move the science farther and faster (Edmunds, Kahn, Payne, & Wilcox, 2017a).

Change Management and Clinical Workflow Research

One of the most significant and unintended consequences of the recent nationwide move to electronic health records, under the Health Information Technology for Economic and Clinical Health (HITECH) legislation, has been the increase in the amount of administrative time clinicians spend providing documentation ("charting") and the commensurate decreases in time they spend with patients and in their professional satisfaction (Payne et al., 2015; Sittig, Wright, Ash, & Singh, 2016). The increase in time is related to the usability of the EHRs themselves as well as the way the use of EHRs fits into the clinical workflow. The amount of administrative responsibility is also seen as a barrier to the advancement of research careers, at least for surgeons (see Fig. 20.3).

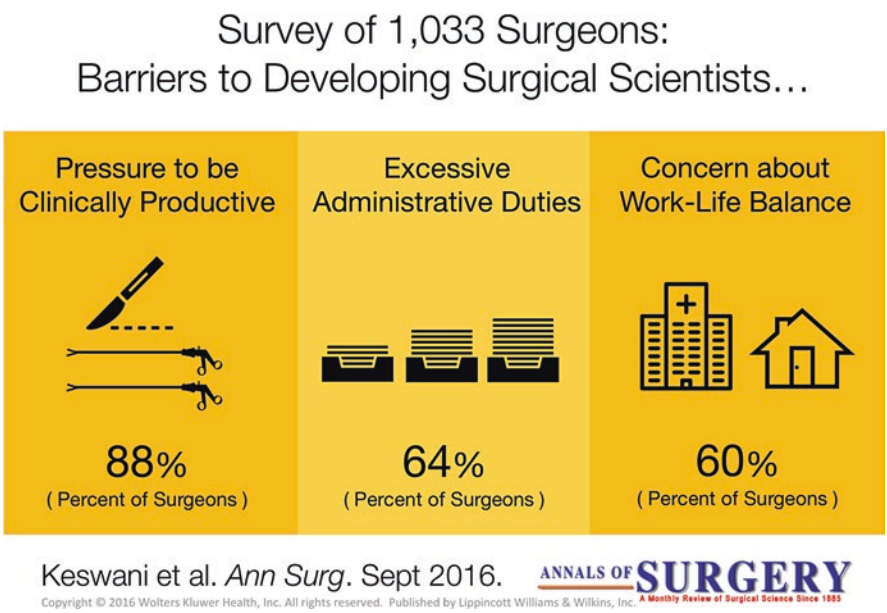

Fig. 20.3 Excessive administrative duties affect time available for research. Source: Adapted from Keswani et al. (2016). Used with permission

Looking back on the hundreds of EHR implementations under HITECH, it seems obvious that the skills in implementing technical systems such as these are not clinical and require an understanding of other fields, such as human factors engineering; organization development, particularly change management; strategic planning; as well as fields that are closer to home, such as quality improvement. Large health systems have been able to designate internal teams and/or hire expert consultants, with varying degrees of engagement of the clinical leadership (Cresswell, Bates, & Sheikh, 2013; Unerti et al., 2010). But limited resources have led many providers in smaller practices to "DIY" approaches, and professional organizations and government agencies have provided toolkits, frameworks, and recommendations to help (e.g., HealthIT.gov, 2017; Middleton et al., 2013; The Pew Charitable Trusts, 2017).

In addition to the glitches and frustrations any other IT implementations can cause, however, errors and delays in clinical workflow and usability can lead to serious patient safety concerns. A complete discussion of health IT and patient safety is beyond the scope of this chapter, but we refer interested readers to *Hacking Healthcare*, by Trotter and Uhlman (2013) for a thorough and practical discussion of ways to eliminate errors in clinical practice. A paraphrased list of some of their recommended best practices includes:

- Survey staff and provide training regarding basic computer skills;
- Study your organization's history of errors;
- Create workflow diagrams that describe real-world processes;

- Create organizationally tailored training materials in collaboration with your vendors (do not use generic training materials);
- Conduct periodic retraining and process audits; and.
- Know your systems' defaults and develop scenarios to test rare events.

It has been noted that workflow research calls for cross-disciplinary teams using a "design thinking" approach rather than "science thinking." In this line of thinking, the current state of the research can be characterized as a kind of cartography (mapping), in which several methods can produce insights depending on the researchers' goals and specific questions (Unerti et al., 2010).

Technology Development Increasingly Driven by User Experience

As an editorial team, we believe that the community of practice interested in the intersection of user experience (UX) innovation and patient-centered research is growing and will provide tremendous benefits to patients, families, communities, and health systems (Hass, 2019). However, we are concerned about the relative lack of investment in research to advance the understanding of UX in general (Payne, 2013), and particularly in areas of clinical practice such as decision support, in which expert systems such as drug interaction look-up services can enhance performance at the point of care. Another area of research where we hope to see additional expansions in funding is in data visualization, from the perspective of the cognitive sciences (O'Reilly, 2017; Payne, 2013).

Technologist, business strategist, and publisher Tim O'Reilly (2017) gives examples of teams working on user-centered services. Inspired by the UK's Government Digital Service, a non-profit start-up called Code for America developed an app for SNAP (commonly referred to as "food stamps") recipients living in San Francisco based on the developers' experiences applying for the program themselves (O'Reilly, 2017, pp. 138–143).

The app not only shortened the application time to 8 min, allowed applicants to attach key documents, and helped applicants to initiate the scheduling of interviews with case workers, but it helped county case workers to stay in touch with applicants through texting and improved the associated workflow so much that other counties adopted it. The app was so successful that it was eventually adopted statewide, a process made easier by the application's adherence to coding and programming standards, which made it straightforward to modify and customize.

This volunteer initiative took a multi-step, uncoordinated application process that frustrated applicants and agency workers alike and turned it into a win-win situation that was more efficient to use, cost-effective to manage, and more satisfying as a process for all involved. O'Reilly sees the shift from the original public agencies' organizational culture to user-centered services as an example of value-based innovation (O'Reilly, 2017, Introduction) achieving the promise of a self-service society working in tandem with social and human services protections and ultimately, with regional governance agencies.

But how to achieve this? Simply put: we are more powerful together. To truly improve health we must see and understand each other, and design systems that fully appreciate individual perspectives on procedural, cultural, economic, and technological issues. Individual contributions add more to the digital whole when accurately informed by a boots-on-the-ground understanding of those being served. In this manner, technological possibilities become innovation opportunities to better serve the ultimate users—patients, caregivers, and consumers.

What's Next?

Here is the consumer health informatics paradox of our times: as our ability to digitally impact ever larger populations expands, providing the ability to "narrowcast" increasingly tailored information and interventions to individuals, the consequences of missteps scale accordingly. Broad-scale interventions become easier to implement, but the interventions can be more difficult to manage when unintended consequences become apparent. Striking a balance between equitable, effective, personalized care and achieving effective economies of scale is a significant challenge.

Moreover, as data reporting capabilities escalate across technologies and care team boundaries, and as the ecosystem of individuals' health data expands to incorporate health care contributors whose records often exist outside of an individual's primary electronic (or comprehensive) healthcare record (dentists, gyms and fitness centers, for example), we run the risks of either overreacting to —or being blind to—the minutiae of continuous data availability. Without a proper understanding of whether a data point is an outlier or an intervention opportunity, we face new hurdles fine-tuning our policy and procedural approaches to make them work for different individuals and systems.

At the same time, the potential opportunities of aggregated data are staggeringly attractive. Artificial Intelligence is poised to provide automated analysis of patients' health data ecosystems on a scale that no single care provider or team could hope to match. In the near future, data-aggregating computers will be able to look across thousands, millions, and tens of millions of patients' fitness, clinical, and life data to identify patterns. These patterns in turn may offer invaluable and unprecedented opportunities for analysis and innovation—again, at scale.

Digital health companion mobile applications are beginning to close the gap between individual condition management and systemic health awareness. Where a medical specialist sees a patient through the lens of their own specialty, we're seeing digital tools emerge that contribute to an individual's understanding of their own holistic health. For example, in the realm of diabetes management, personal condition management data collected by a glucose monitoring application can be aggregated with other disease or condition information by health data aggregating apps like Apple's iphone "HealthKit" and Android's "S Health Kit."

These examples are made possible by technologists and clinical advisors working together and being comfortable with the risks associated with sharing health-related data in measured ways. Also important are adherence to design and development standards and data sharing norms, and defining a vision of collective

benefit that encompasses financial sustainability. The next challenges are finding clinically relevant ways for this data to inform electronic health records, making data relevant, efficient to parse, and supportive of provider decision-making, while ensuring that the innovation loop is iterative so that providers' and patients' experiences inform systemic assessments of clinical relevance and efficacy.

Healthcare practices, public health policies, and public health interventions may be global, national, regional, or local, but they are also intimately individual. Today, tomorrow, and in the days that follow, the narrowcasting and broadcasting of clinical approaches, medicinal interventions, and personal data will provide us rapidly evolving possibilities for increased efficacy, efficiency, understanding, and innovation.

But with change comes an increased responsibility to ensure that as we reach for the global we retain our focus on the individual. Not everyone is interested in, empowered to, or capable of, taking full control of his or her health data, nor will technology itself "save us." Successful democratization of medicine will come when technology supports medicine, not the other way around. Technology in and of itself is not a solution, and innovation is not always improvement.

In sum, as an interdisciplinary field, consumer health informatics works to strike a balance between supporting innovation, intervention, and policy without becoming their master. The individuals and organizations lighting the pathways of our health informatics future—those highlighted in this volume, and the many others outside of it—often share one principle in common, the desire to keep the "human" in human-centered design.

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