

Chapter 20

Back to the Future: Emerging Technology, Social, and Cultural Trends Affecting Consumer Informatics



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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:

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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.healthcarediverive.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

Toward Patient-Centered Hospital Design: What Can Airports Teach Us?



Mullangi S, Ibrahim AM, Chopra V.
Annals of Internal Medicine. May 2017

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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 pre-operative 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.

RCT: Impact of Supervised Exercise before Elective Abdominal Aortic Aneurysm Repair



Barakat et al. *Ann Surg.* July 2016.

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A Monthly Review of Surgical Science Since 1885

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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; Hripesak, 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 health-care 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.).

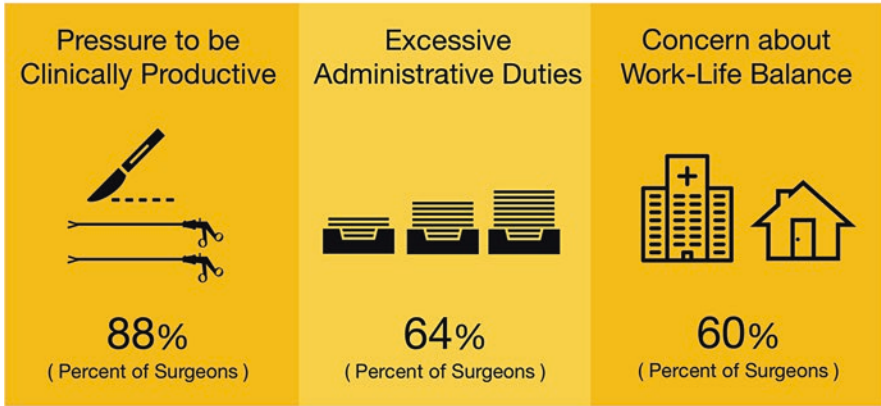
Another model of collaboration is represented by the CIELO platform, which stands for Collaborative Informatics Environment for Learning on Health Outcomes (Payne, 2016; Payne et al., 2017). AcademyHealth's EDM Forum, supported by a cooperative agreement from the Agency for Healthcare Research and Quality (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).

Survey of 1,033 Surgeons: Barriers to Developing Surgical Scientists...



Keswani et al. *Ann Surg.* Sept 2016. **ANNALS OF SURGERY**
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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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