

# Chapter 1

## Disruptive Cooperation: Innovation for Health's Wicked Problems

Jody Ranck

Healthcare systems are in transition worldwide and are feeling the pressure to deliver better outcomes at lower costs. By now, most readers will have heard the statistics. The USA has the most expensive healthcare system in the world based on per capita spending, yet we rank 37th in the world in health outcomes according to the World Health Organization. If we break this down, the numbers are even more sobering. On an annual basis, the WHO estimates that the US infant mortality rate ranks even lower in the global rankings and we are frequently hovering in the 40s for adult female mortality.<sup>1</sup> This is a system that consumes approximately \$2.6 trillion annually, nearly 20 % of GDP. Just to give you an idea of what these numbers mean—this amount is the equivalent of the sixth largest economy on the planet. The challenges to the healthcare system are only growing. In many European and middle-income countries, we find aging populations, prolonged financial crises, and growing health disparities—all demand new solutions and a renewed engagement with health care that can rise above the political polemics. China will see over 10,000 villages with very few residents under 70 years of age in the next decade and will need to find new ways to deliver health care to this aging population. We can no longer afford to have a healthcare system become such a drain on the economy without delivering results in terms of population health outcomes. Rethinking the delivery of health care has become both a sustainable economics question and a public health imperative. For many, the arrival of digital health technologies was going to be the answer to the many challenges

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<sup>1</sup>Christopher Murray and Julio Frenk. N Engl J Med 2010; Ranking 37th—Measuring the Performance of the US Healthcare System. 362:98–99.

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listed above. We argue that they are a necessary part of the solution, but the *social dimensions of innovation are neglected*. **Cooperation is going to be the key driver to realize the triple aim of lower costs, better outcomes, and population health.** Innovation needs to move beyond technology to new ways of thinking about co-creation, co-innovation, the commons, and public goods. These can also drive sustainable business success that also creates healthier populations.

This is not merely a technological issue but demands new ways of thinking about organizational change and the place of technology in these new organizational forms. New business models with complex value chains and ecosystems of stakeholders are needed to address health care's "wicked problems" where no one-off, single-point solution will fix health care's woes. The problems are multidimensional and go well beyond medical care systems—health outcomes are a window into how societies work; there is a health production function that spans social status, environmental drivers, individual choices, and behaviors, as well as the functioning of health systems and our genetics. Precision medicine will need to address the multicausal nature of health outcomes and not just focus on genetics. Wicked problems cannot be "fixed" by single, one-off solutions but require the leadership to marshal together an ecosystem approach and fresh ways of thinking about **designing health systems for desired outcomes**. Health care has yet to succeed in producing a platform that can tie together new business models and services in the manner we have seen Apple, Google, Microsoft, or Facebook. Yet new technologies such as Blockchain may enable new business models and practices for sharing data beyond the data silos that dominate in the present. The notion of a platform that enables new business models and sharing of data across vendors, patients, and providers, and different health systems is becoming an imperative. A major theme of this book is that health care is becoming part of a growing digital service economy, and many lessons on how to build complex digital solutions can come from approaches *informed by design and cooperative business models found in other sectors*. If we build more cooperative business models with the scale and scope to address the complexities of today's challenges, we can begin to think about transforming our health systems to respond to actual needs. Here, we are talking about disruption in the following way. Cooperation means utilizing the tools of co-innovation with communities, patients, and other companies and across competitors, payers, and providers. New technologies slapped on old ways of doing business based on data capture, and creating silos has a limited shelf-life. Competitors, if they think beyond short-term gains, may find that sharing data can enable new business models to be derived from these data that are better capable of improving outcomes. Therefore, the concept of the commons is important. Interoperability does apply not only to data standards but also to organizational interoperability and business practices.

Let us face it, there is an entire health economy that benefits from the dysfunction we find in health systems, and these antiquated business models are slow to change. They will not be replaced overnight, but new entrants into the healthcare space cooperating with more forward thinking health enterprises could prove to be as powerful a motivator to system change as policy initiatives. From a policy

perspective, the old guard that benefited from the sickness economy will need to be de-incentivized, and this includes some of the largest players in health technology whose antiquated business models based on data capture rather than sharing data for the common good should be incentivized into extinction or change their ways, quite frankly. They have become a public health problem as much as they represent a Faustian bargain for large hospitals and providers. Health care is becoming another digital service, which does not mean we have to lose the human component. But leveraging the massive amounts of data for better individual and population health outcomes will not be accomplished via many of the traditional business models. There is a true (r)evolution in meaning and how we think about healthcare delivery. Digital hospitals will have a very different approach that may overlap with current models but will need to extend into communities and homes, for example. Organizational interoperability will count as much as technological interoperability to improve the quality and scalability of health services. In the final days of writing this book, we saw the launching of new partnerships on Blockchain and health care when two technology companies, Gem and Philips, launched a joint venture with a call to bring other Blockchain and health technology companies together. We want to encourage initiatives like this and feel that Blockchain and cooperation could, in the long haul, make a significant contribution to better health systems.

## The Business Case

A tipping point has been reached where the incentives that support the underlying healthcare business model have begun to change—and it has begun already to tilt ever so slightly toward a more prevention-oriented system from the sickness economy that has become unsustainable. Value-based care is a systemic driver that is enabling new business models for prevention. To put it in more human terms, wouldn't it be better to offer a diabetic better preventive care to the tune of \$7000–10,000 than to pay \$65,000 to amputate a foot due to lack of preventive care? We have both technological and non-technological solutions to avoid this type of system failure, but all too often the incentives and coordination of care are not there to prevent these failures. Who gets rewarded for cooperating and coordinating care? New payment mechanisms under value-based care have begun to reward healthcare providers who do a better job of coordinating care and reducing hospital admissions. While this is the beginning, we think much more intellectual and policy work needs to be done to marshal technologies, business practices, and platforms to succeed. We have written this book to offer hope and show that there are solutions to many of the problems we face. We are living in a historical moment of rapid technological change, and the coming years will demand a great deal of more collaboration across the public and private sectors, between patients and clinicians, public health, and medicine. The exciting thing is that many of the technologies we will write about in this book have already demonstrated their

transformative potential for new forms of cooperation and business models in other sectors of the economy. **The innovation we are going to discuss in this book is not just a story about new gadgets and devices, however. We discuss devices and technologies but are making a call for more efforts that demonstrate a focus on cooperation and co-creation can change the way we deliver health care and reconfigure systems to more patient-centric care.**

The technological shift that is beginning to transform our healthcare system, albeit slowly, is different from many of the technological shifts of the past due to a number of concurrent factors:

- The key driver is the growth of mobile phone access, particularly for smartphones in the past 4–5 years, and the computing power embodied by these devices will make them central devices for patients to manage conditions in the coming years.
- We may have reached a tipping point where the cost of health care is viewed as unsustainable in the eyes of all stakeholders across the healthcare value chain.
- Low-cost sensors are becoming quasi-ubiquitous and will continue to grow for the foreseeable future and enable the development of a “health Internet of Things” that includes the medical home, more wired hospitals, and environmental sensors. A great deal of policy innovation is required to minimize the risks associated with these technologies and optimize system transformation. These also carry with them risks and fears of surveillance that will demand both technology innovation and policy innovation.
- The tools that enable us to make sense of the data collected across the ecosystem have begun to scale in ways that can possibly keep pace with the growth in data and knowledge across the health sciences. Yet precision medicine has a long way to go to bridge the gap between the technology infrastructure used in genomics (-omics in general) and the health IT infrastructure that will render these data useful to clinicians and patients.
- Many-to-many platforms as embodied in social media are empowering patients, innovators, and community-based groups to share insights and build communities of interest around health issues. How can we mobilize citizens and civil society to push for the necessary policy and technological changes that have not been effective so far in catalyzing transformational change?
- Governments have discovered new mechanisms to unlock health data and build platforms for individuals and innovators to build new products and services that can address some of the inefficiencies, information asymmetries, and gaps in services that exist in our current fragmented system of care. The time is ripe to take lessons from the experiments to date and build strategies that can leverage these platforms even more with an eye toward transformational change of health systems. Policies need to catch up to technology and cultural shifts so that cloud computing can be better leveraged and incentives for good governance in place. Blockchain growth will only further the need for policy innovations as the capabilities of a distributed, cryptographic ledger enable distributed, autonomous corporations and may render insurance models as we know them in the present, archaic.

What is emerging is more than a one-off technology shift but a new ecosystem of technologies and even policy frameworks that will steadily transform the health-care system over the next decade. *The algorithmic revolution is beginning to transform health care.*

We begin with many of the challenges in the health system, but our goal is to offer some insights into some of the potential directions the system will go in the coming decade. This does not mean that technology has all of the answers for technological solutions also require social, cultural, and political changes to bring about the necessary changes. Despite the challenging political and economic realities in which we find ourselves at the moment, we still have a tremendous opportunity to create a better healthcare system. This is going to be a long-term process, not a simple matter of a single shot at health reform by any single administration, but a long-term transformation of health systems and a revolution in what health and health care *mean* in a digital world. Over the past several years, we have witnessed a dramatic growth in wireless technologies that offer the promise of extending the reach of our healthcare system while offering many early-stage solutions that hold the promise of saving money and lives. For many, this may sound like another round of hype from the technology sector promising riches and futuristic marvels that rarely materialize, except for the few. Many readers have undoubtedly heard this before with genomics and biotechnology from the late 1980s to the present. Biotechnologies would offer a myriad of wonder cures for cancer, chronic diseases, and a host of other diseases. One to two decades later, we have certainly seen many advances in the time and costs it takes to sequence a human genome and there are many new therapies on the market that can save or extend lives. But for the average patient, the “revolution” often appears lacking. Drugs that cost over \$100,000 per year and may extend a life 6–12 months have not reached the bar for counting as transformational unless they have widespread access and dramatically improved outcomes. The biotech revolution has been uneven and has not addressed the fundamental structural problems in our healthcare system. In fact, the prices for biologicals can contribute to pressure on healthcare prices. Digital health technologies have the capacity to bring down the cost of clinical trials and ultimately the price of new drug entities. Innovations, if they are worthy of the label, will need to be measured by their capacity to offer better care to more people at a lower price. Precision medicine will need to evolve beyond genomics to include environmental, social, and behavioral drivers of health outcomes to have the efficacy it promises. Doing this will require ways of building new data commons and the ability to push analytics insights to the point of care and into the home. At present, this is a very challenging order and the health information technology infrastructure is poorly prepared despite marketing rhetoric to the contrary.

The growth in wireless health and health IT in general, if coupled with the right mix of organizational change across the health system, could play a major role in reducing inefficiencies and improving the overall quality of care if we make the right policy decisions and build a collaborative market for these innovations in the coming years. Competition is an important part of what drives innovation

in health care but not the only dynamic that matters. Just throwing technology at health issues and calling it “disruptive” is beginning to lose its luster.

We are in the early days of the wireless health era, but the impact is already visible. Many readers will have already experimented with an app for monitoring their diet, fitness, or a chronic condition such as diabetes. Fitbits have become ubiquitous but are hardly the answer for solving chronic disease self-care. You may have noticed a change in the past one or two years when you entered your doctor’s office and encountered an electronic health record (EHR) for the first time, unless you have been getting your health care from one of the early adopters who implemented EHRs years ago. Many of you may belong to an online patient group or social network where you can share experiences of managing a chronic condition or get involved with a health campaign. Some innovations are more subtle, an app that lets you see the air pollution levels in your neighborhood and determines who contributes to pollution levels in your zip code, for example. Several years ago, having the power in your hand to “see” this information would have been unimaginable. Today, we can use the camera in our cell phones to get a reading of your heart rate and the author is involved with a company that will soon have sensors on the market that offer a full EKG plus several other biometric measures and the sensor can be manufactured for pennies. Hackathons and innovation challenges are proliferating around the world for solutions that can address the chronic disease epidemic or the health challenges of cities. One interesting example is an innovation challenge sponsored by Qualcomm to develop a “health tricorder” that can measure all of your vital signs with a mobile device. These are just some of the examples of the changes that are happening that we will document in the chapters that follow.

We would like to take you a journey across the healthcare system and provide the reader with insights into what the future of the health care could look like in the coming years if we get things right this time around. On many of these fronts, there is no consensus on the best path forward and the contributors to this book have a strong interest in focusing on new approaches to building platforms that can scale and create ecosystems and new business models focused on the triple aim.

## ***How (un)Healthy Are We?***

Before we dive into the technology innovations that concern us, we will take a brief detour into the problems with the US healthcare system. This will provide the context for the unmet needs and challenges for which entrepreneurs are actively developing solutions. We will learn how specific chronic diseases and relatively small numbers of poorly managed conditions contribute to substantial financial costs that we all pay for through higher health insurance premiums and other “taxes.” Social innovation that can bring about policy innovations and organizational change will need to accompany the technologies if we are to drive disruptive change. One of the lessons that the rise of social networking platforms and

data analytics are demonstrating is that health outcomes are often tied to the social networks and communities in which we inhabit. Mobile phones, we will learn, are helping us to understand the social dynamics of chronic diseases beyond the issue of individual choice. Health is a profoundly social issue, and we are only in the early days of leveraging “social technologies” such as the Web and mobile to produce healthier communities. Data mining, when done in an ethical manner, can uncover hidden patterns that may not be observable to the clinical gaze. We will examine research that illustrates the connections between the relative health status of our social networks and one’s risk of being obese or eventually receiving a diabetes diagnosis. This is important to keep in mind as we look at the statistics below.

## The Challenge of Chronic Diseases

We live in a society that is aging. The antibiotic revolution that played a dramatic role in extending life spans after World War II has played a major role in helping to shape the demographic profile of the US population. In 1910, about the time that the architecture of our current medical system was being formed, the percentage of Americans 60 or over was nearly 7%. By 2020, the percentage of Americans over 60 is projected to be over 20%.<sup>2</sup> Many countries such as Italy and Japan<sup>3</sup> are facing severe shortages of caregivers given the demographics of aging that leave a gap in the health workforce that aging in place technologies can help fill. This shift alone translates into an increase in chronic diseases that accompany the aging process. In addition, we have a serious problem in the USA and elsewhere with many suffering from chronic conditions at a younger age. *Chronic obstructive pulmonary disease (COPD) alone will cost \$4.8 trillion globally by 2030.*<sup>4</sup> Childhood obesity rates have skyrocketed as our food system and lifestyles have shifted. When we take a look at the numbers below, the challenge of chronic diseases will appear daunting. But the fact is that most chronic diseases are preventable. It is not too late to change the trends and forecasts if we take can target our energies and resources to bring incentives and policies in alignment around what should be done rather than continue to support the policies and incentives that have created the problems in the first place. Below are some statistics to illustrate just how serious a problem we are confronting and some of the economic statistics associated with chronic diseases are staggering:

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<sup>2</sup>[http://www.aoa.gov/aoaroot/aging\\_statistics/index.aspx](http://www.aoa.gov/aoaroot/aging_statistics/index.aspx).

<sup>3</sup>[http://www3.weforum.org/docs/WEF\\_Harvard\\_HE\\_GlobalEconomicBurdenNonCommunicableDiseases\\_2011.pdf](http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf).

<sup>4</sup>[http://www3.weforum.org/docs/WEF\\_Harvard\\_HE\\_GlobalEconomicBurdenNonCommunicableDiseases\\_2011.pdf](http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf).

- More than 67 % of baby boomers have one or more chronic diseases.<sup>5</sup>
- More than 109 million Americans have at least one of the seven main chronic diseases such as diabetes, heart disease, cancer, or arthritis totaling over 162 million cases.
- The total economic impact of chronic diseases accounts for over \$1.3 trillion annually.
- Chronic diseases account for \$1.1 in lost productivity and \$227 billion for treating these conditions.
- At the current rate, it is projected that we will see a 42 % increase in chronic conditions by 2023 that will contribute to an economic loss of \$4.2 trillion annually.
- Even modest improvements in prevention and treatment could reduce these costs by up to 42 %.
- Prevention alone could reduce chronic disease rates by 27 % and save \$1.1 trillion and save \$218 billion that would have gone to the cost of treatment. The net result would be a \$905 billion increase in GDP.
- 23 million Americans have asthma, resulting in over 500,000 hospitalizations per year, many preventable.
- One in ten people in the USA has diabetes, and approximately 350 million individuals worldwide have been diagnosed with the condition.
- Either over 50 % of prescriptions for drugs are left unfilled or patients do not adhere to the prescribed regimen properly.
- Readmissions after acute care costs Medicare \$12 billion annually and across all taxpayers approximately \$25 billion annually.<sup>6</sup>
- Nearly 75 %, or approximately \$1.7 trillion, of all health spending in the USA per year is linked to chronic heart failure, chronic obstructive pulmonary disorder, and diabetes.<sup>7</sup>
- While the attention has been on the “diabesity epidemic” in the USA, by 2030 the growth in disease rates in middle-income countries will be substantial given current trajectories.

Seventy percent of all deaths are caused by chronic diseases with heart disease, cancer, and stroke accounting for half of all causes of mortality. Pragmatic measures we can use to cut costs. Health care has its own version of a 1 % crisis.<sup>8</sup> Currently, the top 1 % of healthcare users consume about 21.8 % of all health expenditures and the top 5 % of users consume **over 50 % of the overall health**

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<sup>5</sup>2010 Survey of Health Consumers: Key findings, strategic implications. Deloitte Center for Health Solutions, May 2010.

<sup>6</sup>See the Institute for Healthcare Improvement, State Action on Avoidable Readmissions program: <http://www.ihl.org/offerings/initiatives/taar/Pages/default.aspx>.

<sup>7</sup>Stachura, M. and Khasanshina, E. (2007). Tele-homecare and Remote Monitoring: An Outcomes Review (Advamed 2007). Available: <http://www.advamed.org>.

<sup>8</sup>[http://meps.ahrq.gov/mepsweb/data\\_files/publications/st354/stat354.shtml](http://meps.ahrq.gov/mepsweb/data_files/publications/st354/stat354.shtml).



*expenditures*.<sup>9</sup> Many of the factors that drive these utilization rates are social. We often hear now that your zip code tells us more about your health than your genetic code. If we can move the dial in these segments of the population alone by helping them to become healthier before they fall ill with expensive acute conditions, we can make a significant dent in the waste that our healthcare system produces. Just to give the reader an idea of how fast the chronic disease epidemic is growing, we can look at the data for 2000 when we had approximately 125 million suffering from chronic diseases. If we look ahead to 2020, it is projected that 157 million will suffer from at least one chronic disease. Our current system is too expensive to treat and manage all of the cases in a sustainable way over the life course of every patient. Many middle-income countries will have to simultaneously deal with a large burden of infectious diseases as well as growing chronic disease rates, making the need for health system transformation even stronger. The underlying economic model of care combined with the structure of the healthcare system has rewarded payment for rendering of services (fee-for-service model) versus paying for generating good health outcomes. This is beginning to change, and we will need to go farther to reign in costs in the coming years. Digital health solutions will be critical tools for health system stakeholders to succeed in the coming value-driven health economy that will increasingly emphasize prevention and keeping people out of hospitals.

The past system of rewards made keeping people out of hospitals a challenge. In 2007, the Medicare Payment Advisory Committee studied the economics of hospital readmissions for chronic diseases and found that inadequately handling the discharge of patients from the hospital resulted in increased expenditures for readmissions of 17.6 % higher to the tune of \$15 billion annually. Seventy-five percent of these readmissions were deemed preventable.<sup>10</sup> A large number of these preventable readmissions can be readily resolved through wireless technologies combined with new case management systems. These numbers do not even reflect the toll of readmissions on families and caregivers. As we will see later, the economic costs of caregiving have become a major issue in the USA and many readers will be acutely aware of the sacrifices they make in time and income managing the health care of a sick family member or friend.

The sheer complexity of treating people with multiple chronic diseases is a challenge as well. Most treatment guidelines focus on a single disease, and many risk models used to manage patient populations are also based on single or tightly linked conditions. As we age and have to manage multiple conditions, some of the guidelines may actually contradict one another. Osteoporosis may demand more weight-bearing exercise, for example, while guidelines for some diabetics may have the patient avoid weight-bearing exercise. This is where personalized medicine based on a large amount of data from the medical literature combined with one's own personal health data can offer potentially better, more customized

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<sup>9</sup><http://www.nccor.org/downloads/Understanding%20US%20Health%20Care%20Spending.pdf>.

<sup>10</sup><http://www.himss.org/content/files/ControlReadmissionsTechnology.pdf>.

treatment patterns for those suffering from a number of conditions and risk factors. For many chronic diseases, the solution is a shift in lifestyle choices such as diet and exercise but often things such as work, unsafe neighborhoods, and income levels get in the way. Fortunately, many of the tools used in wireless health can also help patients with social supports, building community coalitions, and other forms of social safety nets. We will explore how digital health solutions can take innovative community-level public health programs such as the healthy cities/communities initiative that married city planning and public health in the 1980s and reinvigorate these approaches in ways that can tie individual self-care to population health. One of the greatest challenges to realizing the vision of personalized medicine is the sheer capacity of health IT systems to integrate other types of data from beyond the clinic such as genomic data and patient-generated data. In the coming years, better integration of data, as well as user-friendly tools that provide insights to patients and providers, will be needed so that these data can be acted upon.

## **Aging in Place and Digital Health**

The experience of aging is changing as well. We are living longer, and while many baby boomers live active lifestyles, the number of boomers and those more senior living with multiple chronic diseases is growing. A more mobile population means that it has become challenging for families to take care of a parent with dementia, for example, who may live in a distant city. Managing an aging population is becoming an important social and political issue in our financially challenged times. How can we keep people well throughout their twilight years so that they can continue to lead active and productive lives? There is a growing interest in how to rethink aging and to develop new roles for active seniors. This is an approach that is gaining in importance as many OECD countries face potential trade-offs in the context of the global financial crisis. Health systems can focus on a zero-sum game between the old and young and cut services for the elderly, or take a more holistic view and examine how to use new technologies that enable more active “silver years” and the opportunities this creates. Organizations like the International Longevity Centre are attempting to move beyond the zero-sum mind-set and explore new roles in the voluntary sector for those on pensions or in retirement. Prevention and well-being programs are increasingly emphasized throughout the life course so that the chronic disease burden described above can be attenuated later in life. The life course approach to aging can help us move beyond the zero sum, blame the elderly for bankrupting the system approach, and take a more holistic approach that focuses on lifestyles and behavioral interventions that can reduce chronic disease burdens. Mobiles and remote monitoring can play a very important role in facilitating behavioral changes, even later in life, that can reduce chronic disease burdens as well as making communities more livable for the elderly.

Some readers may balk at the thought of the elderly being mass users of technologies to manage their health conditions. There are several reasons to reconsider preconceived notions about technology and the elderly. First, it is time to take a long-term view of the problem over the next 10–20 years and plan ahead—the past may not be a good indicator of what the experience of aging will be like in 2015. The baby boomer generation has already adopted mobile technologies over the past decade and will likely continue to integrate many of these devices into their lifestyles if the technologies help improve their livelihoods. Second, many mobile technologies are designed specifically for aging patients who may have experienced diminishing dexterity, eyesight, and a number of other capacities. Many remote monitoring sensors will be worn in one's clothing and require little manipulation. Most signs are pointing to the fact that baby boomers are going to push for a very different experience of aging from their parents, and technology will play a big part in this transformation. In fact, aging technologies are becoming a major business opportunity for entrepreneurs looking beyond the newest, hippest device for the 18- to 32-year-old crowd.

Already, a number of wireless solutions are available to address conditions of aging. Unsafe wandering of patients with Alzheimer's increases the risk of injury and death. We can use sensors to monitor the location of those suffering from dementia and Alzheimer's. Falls are another major condition where wireless devices can help. According to the CDC, the economic burden of falls among the elderly will cost the US healthcare system over \$50 billion and nearly 15,000 die per year from falls.<sup>11</sup> Wireless health solutions have been developed to monitor and even prevent falls through technologies such as smart slippers that monitor movements in the house.<sup>12</sup> The "Patient-Centered Medical Home" has proven to be a far more medically effective and cost-efficient way to manage many conditions associated with aging and is facilitated by telehealth and machine-to-machine (M2M) solutions that facilitate the access to a nurse or medical provider in one's home. This is an exciting area of work in the wireless health arena that can fundamentally change the way we experience aging—aging at home rather than in nursing homes. In Japan, the postal service realized that the Internet was resulting in far less mail needing to be delivered, so they equipped postal workers with tablet computers to monitor checkups on the elderly. This type of thinking needs more support and cross-fertilization with technologists, social scientists, and policy-makers along with an engaged citizenry to translate small changes into macro-outcomes.

**Wearable technologies** that were initially developed for the military and first responders are now playing a role in remote care. Armed with sensors that can detect heart rates, respiration rates, location, and even posture, these technologies will be deployed across the spectrum from fitness to aging. Already, we see the

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<sup>11</sup><http://www.cdc.gov/homeandrecreationalafety/Falls/data.html>.

<sup>12</sup><http://mobihealthnews.com/5675/att-develops-smart-slippers-for-fall-prevention/>.

use of sensors in elite European soccer matches and can see in real time the distance run by players, their velocity, temperature, and heart rates. These same tools can be used to get patients out of hospitals sooner and avoid the risk of hospital-acquired infections. Wearables and remote sensors can also be configured to send data to one's caregivers and not just your physician. These effects could be widely felt in the underlying economics of caregiving that has become a major challenge for many families in the USA with aging and sick relatives.

Aging and chronic diseases are not only issues for the afflicted alone. Taking care of sick relatives and friends can be a very costly and time-consuming commitment for approximately 29 % of the US population.<sup>13</sup> The economics of caregiving illustrate how the breakdown in our health system is taking a toll on households who provide approximately \$375 billion annually in uncompensated care (ibid). That is twice as much than is spent on nursing home services and home care. Medical bills cause more than 50 % of bankruptcies in the USA. The average Medicare beneficiary pays an estimated \$45,000 out of pocket for home care expenses each year.<sup>14</sup> According to the study cited above, more than 34 million individuals are providing care to another family member. Valuated at \$10 per hour, this care amounts to more than \$350 billion annually. In countries where extended families live together, the dynamics may be a bit different from the US context, but there are certainly tools that can help ease the burden globally for caregivers. Clearly, people need solutions that can facilitate and coordinate caregiving and offer better care at a lower cost. Even if you are perfectly healthy, the gaps in the healthcare system can have a profound effect on your quality of life. Remote monitoring and wearable technologies can play a role in enabling safer and more meaningful aging in place, but so far aging has been a relatively untapped market for many wearables makers who focus on the young and fit.

## Waste and Inefficiencies

In 2012, the Institute of Medicine released a major report on the state of the US healthcare system.<sup>15</sup> The report highlights the coming perfect storm of dramatic growth in medical knowledge coming up against the growing disease burden and a system ill-equipped to handle the dual challenge of information overload and disease burden. It is easy to blame all of the problems surrounding our system on a single scapegoat—drug companies charging too much, government waste and paperwork, fragmentation of providers, and so on. In reality, there are problems

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<sup>13</sup>Caregiving in the United States, 2009. National Alliance for Caregiving and the AARP.

<sup>14</sup>Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving. AARP Public Policy Institute, 2007.

<sup>15</sup>Institute of Medicine, 2012. Best Care at a Lower Cost: The Path to Continuously Learning Healthcare in America.

throughout the system that stem from the incentives for payment, lack of a data-driven system, and silos that make getting the right information at the right time to the right person next to impossible, to the rising cost of clinical trials and beyond. One of the problems that may not be appreciated by the general public is the challenge of our successes in science and research. The sheer volume of knowledge and data produced by the health and medical sciences is now impossible to fully comprehend by any single medical or health professional. What we are learning is that it is one thing to generate vast amount of medical data and quite another to actually integrate the data into clinical care.

The IOM report suggests that it would take 21 h per day for primary care physicians to provide all of the recommended care for acute, preventive, and chronic care for management needs. In addition to clinical care and keeping up with the latest medical science, physicians spend approximately 30 % of their time on administrative work that has become increasingly complex as the system has grown. It should come as no wonder then that patient care is often fragmented as the patient moves from a primary care provider to specialists. Most often, the tools that we need to coordinate and assist physicians to manage their workflows either have not existed or have not be up to the task at hand. The bottlenecks listed here also play a role in increasing medical errors. Several years ago, the IOM studied the problem of medical errors and determined that 100,000 lives per year are lost due to preventable errors.

In order to provide the highest quality of care, clinicians increasingly need tools that can help them keep up with the rapid rate of growth of medical knowledge and find ways to integrate this information into the workflows of their increasingly busy and chaotic lives in the clinic. This is no easy task. Later in this book, we will take a look at the field of big data and the computing tools that are making it possible to scan millions of pages of medical literature and integrate this knowledge and data with the observations of the clinician to improve clinician's decision-making. Integration of data analytics with wireless technologies will become increasingly common over the coming years. We also have new tools that both clinician and patient can use together to make more informed decisions when multiple therapeutic options are available. These types of tools can both improve outcomes and save money. As more patients utilize wireless tracking devices to monitor their conditions and remote monitoring becomes more ubiquitous, we run the risk of drowning in a sea of data. This is where the role of technologies such as big data and data analytics will become invaluable to manage vast amount of streaming data and to make sense of all of these data. Just collecting data for data's sake does not solve many problems. Fortunately, there are many entrepreneurs and companies working at the nexus of wireless health and data to help the system and individuals manage these pain points. What lies on the horizon is an important shift in medicine. Historically, medicine has been based on retrospective studies and data and episodic encounters with patients. With anytime/anyplace health that wireless devices create, *we are beginning to see the rise of real-time, real-world medicine* based on many data points beyond a single medical encounter. Here, we will see innovations that not only improve the quality of care, but also offer substantial savings and efficiencies across the health system.

The estimated cost of reforming the healthcare system to cover all Americans is \$1 trillion over 10 years, as healthcare futurist Joe Flower observes.<sup>16</sup> He highlights this fact to remind us that inefficiencies and waste account for over \$750–780 billion per year which is nearly *eight times what it would cost to insure all currently uninsured Americans*. Healthcare waste exceeds the 2009 budget for the department of defense. Of the estimated \$600 billion spent on laboratory tests, approximately 70 % of these funds are spent on paperwork. Flower’s insights should bring home the realization of what is possible if we can put into place the mechanisms for creating a rationally organized and managed healthcare system. If we can transition to a prevention economy that can bring down the rates of chronic diseases through wireless technologies combined with more effective behavioral change modalities, decrease medical errors through checklists and sensors, improve physician workflows with well-designed EHRs and clinical decision support, and coordinate care more effectively through the cloud—a lot of “IFS”—but perfectly feasible within a decade. Below, we provide a brief overview of the sources of excess costs in the system identified by the Institute of Medicine in 2010. Many of these are areas where appropriate technologies combined with business practices and incentives could result in tremendous savings:

- Utilization of unnecessary services (\$210 billion)
  - Overuse, beyond evidence-based standards
  - Unnecessary use of higher cost services
- Inefficiently delivered services (\$130 billion)
  - Mistakes, errors
  - Fragmented care
  - Unnecessary use of higher cost providers
  - Operational inefficiencies
- Excess administrative costs (\$190 billion)
  - Insurance paperwork costs beyond benchmarks
  - Insurers’ administrative inefficiencies
  - Inefficiencies due to care documentation requirements
- Price inefficiencies (\$105 billion)
  - Products and services not in alignment with benchmarks
- Lack of prevention services and savings (\$55 billion)
- Fraud (\$75 billion)

One of the perplexing issues with health care is how irrational it appears to the laymen. Trust us, when you devote your professional career to health and medicine, this perception does not go away because the economics of health care rarely fit within prevailing economic paradigms, nor does it resemble anything remotely

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<sup>16</sup>Joe Flower (2012). Healthcare Beyond Reform. Doing it Right for Half the Cost.

rational as the diabetes case discussed earlier illustrates. An analogy often used to get the point across is to imagine if grocery stores were like health care. You would buy your groceries, and after passing through the checkout, you would have no idea what your groceries cost because you would not get a bill for another month or so. Drug prices across hospitals and plans can vary by an order of magnitude or more. There is a great deal of talk about “consumer-driven” health care that assumes that there is a market in health care that resembles some kind of mythical rational market where information on prices is perfectly transparent. The challenge often goes beyond information asymmetries to just plain dysfunctional markets. Joe Flower makes the case clearly when he observes that there are useful treatments for back pain that may cost several hundred dollars and they compete unsuccessfully against alternatives for \$50,000–75,000.<sup>17</sup> In later chapters, we will explore some of the platforms that belong to the Health 2.0 space that are targeting the lack of **transparency** to create more consumer-friendly platforms that enable patients to obtain an accurate estimate of what actual costs will be for a given procedure as well as which providers have the best record of good outcomes for that procedure. One can see through examples such as the XeoHealth and MediKredit Integrated Health Consulting collaboration to automate the adjudication of claims that digital technologies can both cut administrative waste and improve the experience for patients dealing with both health insurance companies and their providers. Dealing with both of these parties is a source of immense frustration for patients caught in the middle. This process is known as “real-time adjudication” of claims, and it is already a reality in South Africa, but feels like a distant dream still in the USA for most consumers outside of the contexts where XeoHealth is deployed.

## **Wireless Health and the Health IT Ecosystem: The Technology that Is Driving Change**

The technologies that are creating the possibilities for health system transformation include mobiles, cloud computing, social networks, data analytics platforms, telehealth, and sensors. Most of these technologies are familiar and have become globalized technologies over the past decade. In fact, in some ways, the USA was behind in adoption of mobile phones for health care compared to some countries in Africa and Asia where the “mHealth revolution” has been underway for nearly a decade. In contexts where health professionals are in short supply, the mobile phone has become a necessary technology for extending the reach of the health-care system into villages. From Bangladesh to South Africa and beyond, we have seen very innovative uses of mobile phones to remind women of when to have checkups for their antenatal care when pregnant, to remind HIV sufferers to take

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<sup>17</sup>Ibid, p. 44.

their life-saving antiretroviral medications, or to collect data on health issues that inform how health systems will allocate resources. It has come as a surprise at times when we spoke to US audiences several years ago about mHealth, and the first question out of the lips of public health academics was that how will the poor use new technologies because they lack access. All we need to do is look at the numbers. Cell phones are ubiquitous in much of the developing world and the USA. Sure, we can find pockets where poverty rates are extremely high and they are not found in 100 % of the population. Smartphones are steadily making inroads globally as well. Even in the USA, we find that nearly 50 % of the population has a smartphone. In the coming years, as Moore's law brings down the price of smartphones, we even expect to find them in very large numbers in places like Kenya. Do not be surprised if in the next few years you come across companies providing mHealth applications and services that originated in Kenya, South Africa, or India.

To give you an idea of just how ubiquitous the cell phone is—probably the most successful technology ever created—we will look at some of the global and US data and you will easily see why the mobile platform is one of the most promising ways to get health information, and care, into the hands of the most people. At the end of last year, according to the International Telecommunications Union, there were nearly 6 billion cell phone subscriptions.<sup>18</sup> This is not the same as saying 6 billion people out of a total global population of 7 billion have access to mobiles due to the fact that many people have more than one.

The Pew Foundation regularly researches the role of mobiles and information and communication technologies in American life. These surveys are useful in creating a reality check of the distribution and use of various devices and their potential for health applications. What is striking is the decline of landlines and how mobiles are increasingly displacing the use of traditional landlines. Cell phone access greatly exceeds other computing platforms in terms of access as the numbers below indicate. In 2015, the Pew Research Center found that 2/3 of Americans are now using smartphones and 10 % of Americans own a smartphone but do not have access to broadband. For many low-income households, the smartphone is the primary source of health information. For the elderly, smartphone use is growing, but we still have a way to go to leverage these tools to improve outcomes in a scalable way with elderly populations. We will examine this challenge later when we dive deeper into the future of aging technologies and we will see a number of creative solutions that attempt to work around this challenge and design products specifically for the needs of the elderly.

Today's smartphones are far more than a phone. Your camera can be used to measure your heart rate. Peripheral devices such as microscopes and diagnostics can turn the phone into a small laboratory to diagnose malaria. An additional sensor, such as the device developed by AliveCor, can enable it to do an ECG, and a company that the author is involved with, Ram Group, will soon have the next

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<sup>18</sup><http://www.itu.int/ITU-D/ict/facts/2011/material/ICTFactsFigures2011.pdf>.



generation of hemodynamic sensors that do far more at an even lower price point. The accelerometer can detect a fall, and sensors in the shoes can detect changes in gait that are predictive of the onset of dementia. Apps have plenty of data to help you do everything from finding a doctor or scheduling an appointment (ZocDoc) to planning your diet. The Withings body scale and blood pressure cuff can track and record your weight and blood pressure on an app on your phone or iPad so that the next time you are in the doctor's office you have many data points rather than a single point to draw upon in his or her diagnostic process. The Apple iTunes store now has over 60,000 apps under health and medicine. The problem is that most are not based on any sound science whatsoever, and only 1 in 50 is connected to a health professional. There is a plenty of room in the marketplace for curators of apps who can help both clinicians and patients wade through the thicket of apps to find those that are based on best practices and science and offer consumers the knowledge to make the right choices on digital health offerings.

**Sensors** are another important technology in today's health technology ecosystem. From RFID tags to sensors that measure temperature, pollutant levels, respiration, location, and countless other indicators, we are beginning to enter a world where the number of phenomena that are being monitored by sensors is exploding. Many of these sensors are connected to the Internet to form what is called "the Internet of Things." In reality, we have a Health Internet of Things when we take into account the remote monitoring technologies, and sensors monitoring health and environmental conditions are assembled together. During the aftermath of the 2011 Japanese tsunami and the nuclear reactor crisis in Fukushima, there was an interesting use of sensors for broader public health concerns that is illustrative. An open source sensor technology developed by Pachube (now renamed as Cosm, then Xively) was deployed by citizens throughout Japan and the Asia-Pacific region to monitor radiation levels. These sensors could transmit data to the Internet, and radiation levels could be monitored by anyone with access to the site. Trust in the Japanese government's public statements on radiation levels was undermined when citizen sensor networks indicated much higher levels than the government would admit. Similar types of sensors are in use in a number of environmental health contexts from China to the UK. These examples illustrate one of the powerful lessons of these new technologies in health—that is, there is a great potential to democratize data collection and public debate over expertise in these matters. No longer will data and the interpretation of data be left in the hands of a small elite. Citizen science is coming and becoming more and more powerful every day. Technologies are embedded in networks of meaning and political action and not just matters for health IT experts to discuss with themselves in digital health conferences.

The number of things connected to the Internet is growing dramatically: Estimates range from 20 billion<sup>19</sup> to 50 billion<sup>20</sup> connected devices by 2020. In

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<sup>19</sup>IMS Research, "Internet Connected Devices About to Pass the 5 Billion Milestone," August 19, 2010, press release.

<sup>20</sup>Djuphammar, Hakan, Ericsson, in Lamberth (p. 9).

2008, the number of things connected to the Internet exceeded the number of people on Earth for the first time.<sup>21</sup> A growing number of these devices are linked to the health sector and may offer new insights into the connections between the body and the environment. Later we will learn how sensors that stream data in real time from remote monitoring devices in the home or in clinical settings can be linked to sophisticated data analytics platforms and lead to important new clinical insights that had been overlooked by clinicians and researchers. The challenge here is the issue of data deluge and having the computing power to make sense of all of the data.

## Health 2.0: Social Networks and Health

The growth and scale of social networks such as Twitter and Facebook have made even many of the naysayers who were skeptics about social media stand up and take note of the potential that social networking platforms can play in health care. We are now seeing a number of successful platforms that connect patients and/or physicians. Some interesting examples that have taken off in recent years include the closed network for physicians, Sermo, that enables physicians to share and exchange clinical insights. The community currently has over 125,000 physicians from 68 specialties with a number of research collaborations through academic research centers. Online communities such as Sermo provide an important forum for clinicians to dialog about innovative strategies, best practices, and research. In this book, we have the founder of **Tabeeb**, a new Medicine 2.0 site that focuses on crowd-sourcing medical insights for difficult-to-solve cases, discuss how social businesses can use cooperation more effectively to create both successful businesses, and solve serious social challenges linked to access to medical care and knowledge.

From the patient perspective, Health 2.0 networks have offered a myriad of communities for patients to find other patients for mutual support and sharing of experiences. Many of these platforms are growing in sophistication as the ability to collect and share data from personal health records (PHRs), tracking devices, and members of the so-called quantified self (people who track activity levels, diet, health outcomes, and often experiment with new lifestyle regimens). The well-known site, PatientsLikeMe.com, has become a beacon for the potential of Health 2.0 sites to build a community of patients and contribute to treatments of diseases. PatientsLikeMe was founded by the brother of a patient who died from Lou Gehrig's disease or ALS. After witnessing his brother's struggle, Jamie Heywood created the site for ALS sufferers to share their experiences. This rapidly evolved into a platform where patients could track the progress of their disease and use of medications. As more patients began to participate, an interesting thing

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<sup>21</sup><http://blogs.cisco.com/news/the-Internet-of-things-infographic/>.

happened. Most physicians will have only had experience treating a small number of ALS sufferers; therefore, they do not have a large number of cases to draw upon to inform optimization of therapies. But when a large number of ALS patients chart their own outcomes as a community, this can provide an amazing resource for physicians to understand individual responses to specific drugs through larger sample sizes beyond their own practice. Eventually, this community of patients entered the fray of what now goes by a number of names including “citizen science,” “participatory science,” and “expert patient-led science” and published some of the first peer-reviewed medical journal articles based on their own findings about commonly used treatments for ALS. Health 2.0 is changing how new scientific knowledge is produced.

PatientsLikeMe is only one of many communities that are now available. Alliance Health Networks, MedHelp, TuDiabetes, Daily Strength, CureTogether, the list could go on for quite a bit. The many-to-many Web or Web 2.0 platforms have created the means for patients, particularly those with rare disorders, to find “communities of practice,” so to speak, where they can link to motivate one another, share their experiences, launch campaigns for cures, and participate in collective research efforts. Some of these platforms have begun to scale reaching over 100,000 individuals in several cases. PatientsLikeMe currently has over 125,000 users and extends well beyond ALS to nearly 500 different diseases or conditions. A personal genomics platform (an early start-up) for crowd-sourcing genetics research, GenomEra, has well over 300 individuals sharing personal genetic data for research efforts. What is interesting about these networks is who is doing the science—patients and laypersons. Open innovation has come to the health and medical sciences in some very important ways. The tools of scientific research, data, and platforms are democratizing who can do what. Even in relatively new technology areas such as big data, there are open source and inexpensive ways for laypersons with training from open courseware or Massive Online Open Courseware (MOOC) such as Coursera and Big Data University (IBM’s online training platform for their big data tools) to analyze large datasets or conduct data mining on Twitter and other social networking platforms.

One of the technologies that are enabling mobiles, social networks, and big data to drive structural changes in health care is the cloud. **Cloud computing** is essentially the use of hardware such as servers and software to deliver computing services over the Internet.<sup>22</sup> Rather than installing software on your computer, a method that is increasingly viewed as “old-fashioned,” you log into a Web site and can utilize the software online. This is referred to as software-as-a-service, but one can find a number of different types of cloud services including platform-as-a-service, data-as-a-service, and API-as-a-service, and recently, Microsoft and IBM began offering Blockchain-as-a-service. The significance of the cloud is that it offers the opportunity to scale computing power and share services more readily. This is why the cloud is critically important to health care. In our discussion on

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<sup>22</sup>[https://en.wikipedia.org/wiki/Cloud\\_computing](https://en.wikipedia.org/wiki/Cloud_computing).

inefficiencies, we noted the fragmentation in the healthcare system that most often leads to data locked in silos where it remains unused or difficult to access. Why spend money collecting data if we do not use it to improve the quality of care? For too long, security of data trumped ease of use and access by the right people. This is beginning to change, and we are beginning to see a great deal of innovation at the nexus of data and the cloud that will enable us to do things in the healthcare system that were quite challenging before. Security and privacy will remain important concerns, but no longer can we hide behind the firewalls of security and leave the quality of care to suffer. Over the next few years, as healthcare providers are incentivized to coordinate care and are paid for performance rather than strictly by a fee-for-service reimbursement mechanism, the cloud combined with powerful data analytics will be crucial to the economic and medical success of medical practice. Cloud computing provides the connective tissue to share patient data and manage care remotely and a platform for analyzing the data. Consumer-facing tools in the mHealth space are also reliant on cloud computing via their apps. Data stored in the cloud will be the glue that ties healthcare providers and patients working together to improve health and well-being.

### *The Algorithmic Revolution in Health care*

The political economist John Zysman from the University of California at Berkeley has been studying various “digital revolutions” over the past two decades and the growing role for algorithms in various parts of the economy. Many services in the economy are gradually being transformed into codifiable and computable processes and implemented by IT tools.<sup>23</sup> Algorithmic revolutions are accompanied by service revolutions, and these are not the services of “service economies” past that are low-wage, low-value-added nature. These are the new engines of economic productivity and offer the opportunity to transform entire sectors of the economy into new business models, new ways to organize the firm, new skills and knowledge assets, and even new classes of professionals. Algorithms are automating many tasks, including many of the processes involved in health care. This book is essentially the story of the algorithmic revolution in health care and how it will transform the way we think about health care, how it is provided, and where value will be created in the future.

The algorithmic and service revolutions typically blur the boundary between the product and the service. Think about Apple and the introduction of the iPod in the early 2000s. The innovation really was not just about the iPod but the combination of the iPod and iTunes together. In one swoop, Steve Jobs and his colleagues at Apple figured out how to get your credit card number in exchange for access to entertainment on their product. This was a very different business

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<sup>23</sup><http://brie.berkeley.edu/publications/wp171.pdf>.

model and service from what came before and had a dramatic effect on how we experience music. The App Store has had a similar effect. The iPhone once again introduced the concept of the App Store and an entire eco-system of apps otherwise known as the App Economy. A few short years since the introduction of the iPhone 3, we have largely forgotten how this innovation fundamentally reshaped the market for cell phones. Android has had a similar effect, but in the open source arena that increasingly competes with Apple. Platforms connect producers of content with the consumers of content and have fundamentally transformed the economy if we think about Google, Amazon, Facebook, and Apple. Why hasn't this happened in health care yet and what kind of platform could transform the current non-system into one that better serves the needs of patients and providers? We hear much talk about the Uber of health care, but I am guessing we need to search for a different model that takes health equity and fairness into consideration. Health is a public good and just calling it "consumer-driven" so we can take more out of patients' pockets will not work either.

Health care is in the early days of a similar technological revolution, but the trajectory will likely be very different. The closed system of Apple resembles the legacy systems of eHealth technologies that are part of the problem that many new start-ups in wireless health services are attempting to disrupt. Apple is beginning to do some interesting work in digital health with the introduction of apps such as ResearchKit, HealthKit, and CareKit. However, an open eco-system that has a similar effect of enabling consumer-friendly generation of data, *sharing of data*, integration of data, and analytical capabilities that create actionable insights could be a major game changer and is more relevant to health care than the proprietary model that Apple espouses. The platform wars for digital health have already begun as by mid-2014 Google, Apple, Samsung, WebMD, and Microsoft have all announced major initiatives with the first three being the most aggressive in the race to become the central system integrator for health and/or wellness data. In a sense, we are living in the version 1.0 Era of the algorithmic revolution where we have lots of devices collecting data. But no single player has quite yet become the "health layer" to integrate all of these data, make sense of it, and offer the data-as-a-service in a manner that is the game changer for patients, clinicians, and the health system in general. One can see elements of this in the current ecosystem where service providers like RunKeeper enable users to track and share data from their workouts, but also integrate data from various fitness devices and trackers such as Withings scales and blood pressure cuffs. Qualcomm has developed the 2Net hub to integrate Wifi- and Bluetooth-enabled health devices in the home via a simple-to-use plug-and-play device. We will likely see new entrants into the healthcare marketplace often from unexpected quarters. That smart TV that you have read about in Wired Magazine can become a portal for the delivery of health content in the medical home (although we need to first figure out what to do about inadvertent messaging about one's Viagra prescription during your Thanksgiving football viewing with family and friends!). Those medical devices previously used in the hospital might become much more desirable devices when the Apple's

and other consumer electronics companies decide to redesign them for the mass market.

But beyond the devices and gadgets, it will be important to not lose sight of the key challenges and opportunities that the algorithmic revolution in health care will touch. Opportunities for more personalized therapies and lifestyle coaching based on one's multiple streams of health data—genomic, lifestyle, fitness, biomarkers, prescription history, environmental context, and social network analytics (strength of social ties, social cohesiveness of neighborhoods, walkability, and built environment)—all can be influenced by feedback loops that the combination of data and technology will empower. For example, at UCLA, the Personal Environmental Impact Report platform utilizes sensors to track your movements and environmental context to provide insights on pollutants that may trigger your asthma based on geolocation but **also tracks your** contribution to environmental pollutant levels based on your driving behavior.<sup>24</sup> TicTrac is another service that facilitates aggregation of tracking data, but still, the data feedback services have a way to go before becoming a truly robust data service. The missing component of the current generation of wearables is the personalized coaching that makes sense of data beyond pretty data visualizations and offers feedback to the user. We are beginning to see algorithm-driven services such as these through coaching engines and services offered by Performance Lab (New Zealand) and Omada Health in the USA. We still have a long way to go, however.

What is emerging is a new paradigm of personalized medicine or Personalized Medicine 2.0. The first generation of thinking in this area was fueled by the biotech revolution from the late 1980s into the early 2000s up to the mapping of the human genome. In 2003, systems biologist Lee Hood coined the term “4P Medicine” where the 4Ps were the following:

- Predictive
- Personalized
- Preventive
- Participatory

His vision was informed by biology, but he recognized early on the need for more robust IT systems in medical research and health care. The vision is one where genetics can provide early detection of illness based on one's individual genome and then take action to prevent the onset of illness for many diseases that have a lifestyle or curative dimension available. This would require the active engagement of the patient. Since he originally developed the concept of 4P Medicine, much has changed on the IT front, however. The participatory nature of the social Web or Web 2.0 plus the integration of data points from outside the body such as environmental data, social network analysis, and the mobile platform has grown such that 4P Medicine can have an even more systemic or integrative vision that

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<sup>24</sup>[http://www.eecs.ucf.edu/~turgut/COURSES/EEL6788\\_AWN\\_Spr11/Papers/Mun-PersonalEnvironmentalImpactReport.pdf](http://www.eecs.ucf.edu/~turgut/COURSES/EEL6788_AWN_Spr11/Papers/Mun-PersonalEnvironmentalImpactReport.pdf).

ties together genomics, environmental health, and the so-called socialization of illness (i.e., the role that social determinants and social networks and supports have in both the spread of chronic diseases and role in disease management). For the biologists out there, we have a more expansive possibility with wireless health to integrate the genome with the other systems: metabolome, microbiome,<sup>25</sup> environmentome, connectome,<sup>26</sup> and diseaseome.<sup>27</sup> This is a long-term process but where we are most certainly headed in the coming decades. In other words, personalized medicine needs to have a much stronger digital services role that can integrate these other data streams from the environment, behavior, and social context with one's genomic and medical data, so true personalization can happen while also enabling population-based health approaches to grow as well. The new era of value-based care is making population-based approaches more valuable and they could be made much more cost-effective and therapeutic with better data analytics built upon diverse data streams. Personalized medicine and population health management do not necessarily have to be at odds with one another. Some ethicists are concerned about the focus on personalized medicine that may exclude population-based approaches, but we believe that the cooperative approaches espoused in this book can offer bridges between the two and ease this tension. True platform strategies, if designed with the right incentives, could drive innovation across these two poles as well.

The insights from both the sciences and how our social interactions are increasingly mediated through the Web are offering up a very different paradigm for health. If we bring together the notion of more expansive personal health ecologies or resources that people now draw upon to manage and understand their health and well-being; open innovation that has opened up the walls of the laboratory and company to novel sources of knowledge and innovation; and the vast eco-system of digital or wireless health technologies, we are actually entering into a new world of "Open Health." One interesting data point to consider here is the example of Foldit, an online game developed by researchers at the University of Washington in 2011, which was developed to solve a scientific problem that professional researchers had failed to solve for more than a decade. The challenge was to understand the three-dimensional structure of enzymes important for the development of novel therapeutics for HIV. Foldit was developed as an online game where laypersons could rapidly learn how to manipulate 3D models of proteins online. Large numbers of online participants played the online game and essentially solved puzzles by manipulating the proteins by following the simple

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<sup>25</sup>For a general overview of the microbiome written for the non-specialist, see Michael Specter's "Germs Are Us" in the New Yorker: [http://www.newyorker.com/reporting/2012/10/22/121022fa\\_fact\\_specter](http://www.newyorker.com/reporting/2012/10/22/121022fa_fact_specter).

<sup>26</sup>[http://www.ted.com/talks/sebastian\\_seung.html](http://www.ted.com/talks/sebastian_seung.html).

<sup>27</sup>Melanie Swan, 2012. *J. Pers. Med. Health 2050: The Realization of Personalized Medicine through Crowdsourcing, the Quantified Self, and the Participatory Biocitizen*. 2, 93–118; doi: [10.3390/jpm20300093](https://doi.org/10.3390/jpm20300093).

game mechanics built around the physics of the atomic structures. They helped build insights on the “recipes” for protein structures by playing the game which in turn helped build algorithms that were more effective than the most commonly used bioinformatics software. They pulled this off in weeks without formally understanding exactly what they were doing.<sup>28</sup> Game players illustrated how very complex solutions could be discovered at a fraction of the cost of conventional science if they only had the proper environment and systems to collaborate. This illustrates the power of co-creation and crowd-sourcing to solve medical problems. We explore this later in the book in our chapter by Osama Alshaykh.

Engaged patients using sophisticated tracking tools; peer-to-peer platforms for sharing ideas, data, and knowledge; gamification in both wellness and research; tools for generating greater transparency in health care and medicine; new data commons; and crowd-sourcing and crowd-funding models—these all intersect with the innovations in wireless health in transformative ways. In the mid-1990s, anthropologist Paul Rabinow wrote a seminal essay on new forms of sociality that were arising out of the growth of biological knowledge.<sup>29</sup> He termed this change *biosociality* to explain how people are connecting and identifying themselves increasingly on the basis of biological knowledge such as one’s disease status. The trends and developments we are documenting in this book are the next stage of biosociality—when it becomes digital or digital biosociality and how this will shape health care in the future. This is a world with greater participation by patients themselves in research and setting up the research agenda for collecting the data. Biosociality will also demand new thinking on ethics and politics as well. The ethics of algorithms and where and which humans intervene to avoid discrimination, gender bias, and racism that can be embodied in the categories used for data and data collection will need much more consideration.

While we often focus on the health policy agendas that are set from above, what is important here is how more bottom-up engagement is accelerating, thanks to the democratization of knowledge. Influential “ePatients” have become spokespersons for what they view as wrong with the current health system and are actively involved in developing the technologies, policies, and social communities that will shape the future. This will no doubt be viewed as threatening in some quarters used to the maxim that “doctor or scientist knows best.” Other physicians and scientists will recognize the opportunities, as well as the dangers, and figure out ways to harness this energy to improve the quality of care and the development of new therapies and even address the financial dilemmas that our health-care system raises. We increasingly hear critiques of smart cities initiatives as too technocentric and top-down and in need of greater citizen engagement. But citizen engagement is not easy and will never be the cure-all for these initiatives, but we

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<sup>28</sup><http://blogs.discovermagazine.com/notrocketscience/2011/11/07/computer-gamers-foldit-protein-algorithm/>.

<sup>29</sup>Rabinow, P. (1996) “Artificiality and enlightenment: from sociobiology to biosociality” in *Essays on the Anthropology of Reason*. Princeton: Princeton University Press.



must still work on solutions that begin small and can scale in ethically appropriate ways. Cooperation is often messy, hard to manage, yet necessary. As we travel in this new landscape, we will need to develop the analytical tools to sort the hype and hope from the realities. Our health system is not an easy beast to tame. In fact, many start-ups have been eaten alive by the fragmentation and perverse incentives. We cannot always believe the breathless hype of technology blogs promising new revolutions in a single platform or new technology. It is a system after all, but we have decided to write this book at the current conjecture because we truly do believe it is an important tipping point for medicine and health care. More than ever, we need strategic and innovative forms of cooperation to actually deliver the promise of better care in an affordable manner. This is something both sides of the political aisle and stakeholders across the political spectrum can find common cause in fixing a broken system. Earlier in this chapter, we mentioned how most healthcare challenges are examples of “wicked problems” where no single approach will solve the problem. There may never be a drug to cure obesity, stress, or the health consequences of poverty. Therefore, having the leadership skills and creativity to drive innovation that entails moving complex value chains and systems (even eco-systems) of stakeholders to align their business models and strategies may require skills that few of us have learned in the university or even in the firms where we work. We want to show in the chapters that follow that we do not need to reinvent the wheel when it comes to cooperation, but rather we may need to change mind-sets about who and how health care is delivered, what we value in health and well-being, and how we work, as societies to produce better health outcomes. What this points to is the innovation in *meaning* that will need to accompany the devices and business models that transform health systems in the future.

**So what is disruptive cooperation?** Helga Nowotny<sup>30</sup> in her meditation on innovation notes the distinction between “the new” and innovation. She makes the observation that in European–American sign language, the sign for the future points forward, but in African sign language, it points to the rear. We see the future through what appears in the past and present. We cannot start from scratch with health system transformation and have to work with the structures that are present. Our “workarounds” are working around what we have already created. But digital health and design, when done right, should aim to design for desired health outcomes rather than purely on existing healthcare infrastructures. This approach will undoubtedly be dismissed by those who see the legacy technology players in health care and the electronic health record providers, for example, as an unshakable cartel. But we beg to differ. We see the seeds of cooperation in the growing use of crowd-sourcing, open innovation, DIY health, and new ways of thinking about the Internet that Blockchain, as one example, provides, as opening up new opportunities. Transforming systems will require a myriad of actors, public–private partnerships, business model transformations to move from fee-for-service to value-based care, and a world of population health management. Managing

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<sup>30</sup>Helga Nowotny. 2008. *Insatiable Curiosity. Innovation in a Fragile Future*. MIT Press.

complex partnerships and eco-systems requires leadership capable of communicating solutions across eco-systems with widely different worldviews and opinions on the problem, as well as an ability to revisit assumptions about how health care operates, a difficult thing to accomplish as the Obama Administration has learned. Nevertheless, there are tools and approaches coming from outside of health care that could provide a platform to build complex solutions and platforms that can make the challenge easier to surmount than we often think *within health care*. Nowotny thinks *we need to oscillate between seriousness and play, science, and irony, and we would add competition and cooperation, the market, and public goods, to build a better future for health care*. Innovation in health care cannot be just a new fashion trend for new apps and devices alone. If we took existing products off the shelves and optimized use of them within well-functioning systems, we could easily hit the triple aim of quality care, access to care at a lower cost. Unfortunately, a legacy of perverse incentives, structural dysfunction, antiquated business models, and the world beyond health systems makes this far more difficult than it should be. The leadership to manage complex forms of cooperation is urgently needed, and we hope this volume can provide at least a few tools to help others think in new ways. We cannot escape the systems of the past, nor do we have to be completely bound by their constraints. We hope this book is a start for building new conversations across the divides and disciplines that often keep us from thinking about health systems and can contribute to building more patient-friendly, real-world, resilient, and accountable health systems in the future.

I will end this introduction with a brief parable and autobiographical note about political change. In 1989, I was a graduate student in Bologna, Italy, and in January of that year, I visited Prague, Czechoslovakia, and befriended a young journalism student. In July 1989, I returned to spend a week with my new found friend. On each end of that week, I had the opportunity to witness the fall of communism in Hungary and Poland as political forces came together to dismantle the communist regimes. On the way from Hungary to Poland with a stop in Prague, I smuggled a copy of Newsweek that had an interview with the former National Security Advisor to President Jimmy Carter, Zbigniew Brzezinski. Professor Brzezinski, with whom I took a class with merely two months later, was quoted for predicting that the Czech regime would fall within two years. I showed the article to my Czech friend who scoffed, "It will take twice as long as that, the regime is in firm control." Fortunately, several months later, I received a letter in the mail with a flyer that was used to call the citizenry to the streets and protest the brutal behavior of the regime. The Velvet Revolution had overturned the regime with little bloodshed. No one predicted this. The pervasive feeling one has working on health care often leaves one feeling that poorly designed technology is our destiny. But poorly designed technology is not safe for patients, drives up the cost of care, and leads to negative experiences of health care and wellness for the entire population. We can do better, and accepting the status quo is no longer acceptable. As healthcare professionals and citizens, it is time that we think beyond the hubris of "there is an app for that" on the one hand and tolerating the status quo on the other. In 2015, the former head of the National Office for the Coordination

of Health Information Technology (ONC) made a call for a “day of action” where one million patients would demand that provider systems provide access to their health data. The fact that this cry even needs to be made is, well, ridiculous and illustrates the lack of leadership in health technology. It is embarrassing. If health care is going to become truly patient-centric, it just cannot be left to headers on PowerPoint decks at health IT conferences and we need to develop the tools that actually engage citizens in healthcare technology design and the co-creation of health outcomes in a manner that is equitable and not just cost-shifting. This would be disruptive cooperation.