

# USING PERSON-CENTERED HEALTH ANALYTICS TO LIVE LONGER



Leveraging Engagement, Behavior Change,  
and Technology for a Healthy Life

DWIGHT MCNEILL

Praise for  
***Using Person-Centered  
Health Analytics to Live Longer***

“This book helps readers understand the brave new world of digital health improvement tools and then use that understanding to improve their own lives. Its focused guidance constitutes a bold new entry into the traditional health improvement literature.”

—**Michael L. Millenson**, author, *Demanding Medical Excellence: Doctors and Accountability in the Information Age*

“This book helped me realize what all the hype about person-centered health analytics means for me. McNeil has blended academic analysis and practical instruction, ensuring that readers can both understand the new technology landscape and take meaningful advantage of it. The result is an important text for anyone looking to take an active role in managing their own health at a reasonable cost in the twenty-first century.”

—**Lauren A. Taylor**, co-author, *The American Health Care Paradox: Why Spending More Is Getting Us Less*

“Dwight McNeill has integrated a variety of streams of thought and research to make a compelling case that person-centered health technologies and strategies can make a real difference in improving health outcomes.”

—**Stuart Altman**, Sol C. Chaikin Professor of National Health Policy at the Heller School for Social Policy and Management at Brandeis University

“Dwight McNeill’s book marks a new step in our collective understanding of the relationship between health and the vastly complex health care system that consumes so much of our national attention and wealth. Health care purchasers are looking for a way to link together their efforts to promote wellness and personal engagement with their investment in the hugely expensive medical care system. This book shows that we can focus on the emerging ways to manage our personal well-being while leveraging the health care system for its particular strengths. It is valuable to all of us as patients, consumers, and families—and will outline a new direction for purchasers, payers, and policymakers trying to set a fresh course for U.S. health care.”

—**David Lansky**, Chief Executive Officer, Pacific Business Group on Health

“The possibilities of data and analytics to change how we live are only understood when translated into human applications. Empowering individuals to participate in, and even shape, their own medical outcomes is among the most compelling and feasible ways that analytics is affecting us all. McNeil has developed the owner’s manual for living a better life, powered by analytics.”

—**Jack Phillips**, CEO, International Institute for Analytics

“*Using Person-Centered Health Analytics to Live Longer* emphasizes the importance of providing tools to people to equip them to be successfully engaged in improving their own health. It provides these tools and recognizes that people cannot do it alone and that others can make important contributions. Dr. McNeill provides innovative guidance to stakeholders on ways to overcome barriers to make personal analytics more accessible and effective for prevention and treatment.”

—**Chris Gibbons**, MD, MPH, Chair of the Board of the Center for the Advancement of Health and Professor at Johns Hopkins Schools of Medicine and Public Health

“Fixing today’s issues with health care requires both individual behavior change and a unity of purpose among all stakeholders—payers, providers, analytics, and regulators. ‘Person-centered’ must progress from its status as a buzzword to an organizing principle for real solutions with data at the core. *Using Person-Centered Analytics to Live Longer* provides important insights for improving population health in the twenty-first century.”

—**David Wiggin**, Direct of Industry Marketing, Teradata

“Dr. McNeil provides a thought-provoking and timely contribution to the field of health analytics. His approach is novel and pays attention to the important issues surrounding person-centered data and its potential to promote positive changes for the health of populations. A wealthy read for students of analytics and health alike.”

—**Robert J. McGrath**, Ph.D., Everett B. Sackett Assoc. Professor & Chair, Director of Graduate Programs in Analytics, Department of Health Management & Policy, University of New Hampshire

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Health Analytics  
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Dwight McNeill

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Editor-in-Chief: Amy Neidlinger  
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Pearson Education, Inc.  
Upper Saddle River, New Jersey 07458

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Printed in the United States of America

First Printing April 2015

ISBN-10: 0-13-388997-1

ISBN-13: 978-0-13-388997-0

Pearson Education LTD.  
Pearson Education Australia PTY, Limited.  
Pearson Education Singapore, Pte. Ltd.  
Pearson Education Asia, Ltd.  
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Library of Congress Control Number: 2015930430

*To all my readers in their quest to achieve good health. To borrow a phrase from the inspirational song **Brave** by Sara Bareilles, “Honestly, I want to see you be brave”. Take control, get engaged, become free, rely on your strengths, use the tools, and don’t give up...ever.*



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# Acknowledgments

This book was made possible through the hard work of others. I stand on the shoulders of many thinkers and leaders, and I kneel in thanks before those who have provided support and kindness.

I pay tribute to Jessie Gruman who, through her wisdom and personal power, gave patients the hope, confidence, and skills to become engaged in their care. She died in 2014 after a lifelong relationship with cancer. She was a great friend and mentor.

I thank disruptive thinkers including Eric Topol, who demonstrated in his book, *The Creative Destruction of Medicine*, how people can take more control of their health through the digital transformation of medicine; and Clayton Christensen et al, who make the solid case that health care will be upended by new organizational entities that appreciate the consumers' demand for convenience and value in their book *The Innovator's Prescription: A Disruptive Solution for Health Care*.

I thank policy implementers like Farzad Mostashari, the former head of the Office of the National Coordinator for Health Information Technology, for his leadership in the development of HealthIt.gov, which is a great resource for patients and their families.

I thank the researchers who have documented the facts about the poor health status of Americans and the related causes, including the US Burden of Disease Collaborators and their landmark paper in *JAMA* in 2013.

I thank integrated delivery systems, such as Kaiser Permanente, that focus on value over volume, respect and include patients as partners in health, and implement electronic health record systems, member portals, and digital devices to inform and activate people.

And I thank the innovators and technology developers, especially those who stand behind the 46 tools and resources in the person-centered health analytics toolkit, for their creativity and perseverance.

I could not have completed this book without the support and kindness of important people in my life. I most appreciate my wife of 42 years. She listened to weird ideas, lifted my mood, corrected

clumsy writing, and offered the greatest insights. She tolerated my obsession over writing the book, every day, every holiday, and every vacation day missed. She was always kind. Similarly, my children, Carly and Jameson, supported me in their own special ways to help me stay on course.

# About the Author

**Dwight McNeill** is a teacher, writer, and consultant. He is a Lecturer at Suffolk University where he teaches courses in population health and health policy.

Dwight has published two previous books on health analytics, including *A Framework for Applying Analytics in Healthcare: What Can Be Learned from the Best Practices in Retail, Banking, Politics, and Sports* and (editor) *Analytics in Healthcare and the Life Sciences: Strategies, Implementation Methods, and Best Practices*. He has also published many journal articles, including “Building Organizational Capacity: A Cornerstone of Health System Reform” (with Janet Corrigan) in *Health Affairs*.

Over his 30-year career, he has worked in corporate settings, most recently as Global Leader for Business Analytics and Optimization for the Healthcare Industry for IBM, and previously at GTE; government settings at the federal (Agency for Healthcare Research and Quality) and state (Commonwealth of MA) levels; analytics companies; and provider settings. He consults on analytics innovations to improve population health management and person-centered health.

Dwight earned his PhD from Brandeis University in Health and Social Policy and his MPH from Yale University in Public Health and Epidemiology.

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## Introduction

**Are you worth it?** The American way of producing health is failing. The United States ranks twenty-eighth out of 34 OECD (Organisation for Economic Co-operation and Development) countries in producing a long life as measured by years of life lost due to premature mortality.<sup>1</sup> This translates into 36 million years of life lost every year. When economists put a value on a year of life, at about \$71,000,<sup>2</sup> the monetized value of the years of life lost is \$2.6 trillion. This is nearly equivalent to annual health care expenditures of \$2.8 trillion. The paradox is that the United States spends considerably more per capita on health *care* but much less than peer countries on *health*.<sup>3</sup> The truth is that producing a long and healthy life is not on any organization's mission statement but our own.

How do you put a value on your life? Certainly, it is “priceless” but let's get specific. At birth, we are given the gift of life. This gift amounts to an average of 79 years for a person born in 2012 with a lifetime value of \$5,530,000. For 99.9% of us, it is the most important asset we will ever have. What we make of the birth gift is largely dependent on the choices we make. But, that it is not the whole story. There are people, organizations, societal structures, and luck that weigh in that can make a big difference.

**People need to rely on themselves more.** Producing a long and healthy life and capitalizing on our lifetime worth are high priority for us but not necessarily for others. The health care system is focused on sickness, not health; on services, not outcomes; on medicine, not on prevention or social determinants of health. Governments concentrate on insurance coverage and reducing expenses, including slashing budgets for public health, which focuses on the emergent—for example, one Ebola death in the United States—but not as much on the important—for example, more than a million

deaths each year attributed to lifestyle behaviors. Government attempts to improve health through social programs are beaten down with socialist rhetoric and contempt for redistributing wealth. Food, alcohol, tobacco, and marketing companies seduce us with tasty but very harmful foods, play to our hopes through advertising, and keep us coming back for more by getting us addicted.<sup>4</sup> Finally, in many respects, technology innovators just don't get it. They are more interested in making us click than understanding what makes us tick.

**This book is about** helping people live a longer and healthier life by using person-centered health analytics to master five behaviors of everyday life that cause and perpetuate most chronic diseases. It is an action-taking book. It defines a future state where people coordinate the attainment of their own good health within the context of a person-centered health culture. It describes the compelling drivers that make person-centered health and the analytics that support it an inevitable resolution for what ails American health and health care today. It goes beyond a call for action and provides a person-centered health analytics (pchA) toolkit to empower, enable, and equip people with 46 tools and resources to optimize their health. And, it realizes that people cannot do it alone and that stakeholders can facilitate or resist the adoption of pchA. It identifies key barriers to the widespread adoption of pchA and offers a portfolio of nine opportunities for stakeholders to craft into plans to benefit people as well as their own bottom line.

**It is different from others books.** First, it is three books in one:

- It provides a *framework* for understanding why person-centered health analytics is important by describing five convergent realities:
  - The American way of producing health is failing.
  - People are getting more engaged as the drivers of their health.
  - Converging trends demand it.
  - Everyday behavior changes are the interventions that matter.
  - Analytics provide new insights to catalyze it.
- It provides a *handbook for people*, which includes information, tools, and a quick reference guide to resources that people can use on their own.

- It provides a *guidebook for stakeholders* to understand person-centered health from the person's perspective, describes how analytics can contribute, and explains what they can do to support it.

Thus, this book provides perspective, a framework, tools, and a path forward for people and their stakeholders, including providers, payers, health companies, technology companies, and government.

Second, it is an action-taking book. Other books that address similar themes of empowering individuals in health address more macro themes. For example, Topol, in a postscript to his book, *The Creative Destruction of Medicine*, defends criticisms that he did not spell out what consumers should do by saying that his goal was “to lay out the reasoning for why and how medicine should be schumpetered.”<sup>5</sup> He provides general guidance for consumers saying, for example, “Consumers coming together to demand a new, individualized medicine will be the most powerful means of changing the future of health care.”<sup>6</sup> Providing a handbook for consumers was not the purpose of his very successful book. Similarly, Christensen, Grossman, and Hwang in their landmark book, *The Innovator's Prescription*, place a lot of emphasis on motivating patients to be more engaged through monetary incentives by concluding that “financial health is a much more pressing job-to-be-done than physical health.” Their solutions include high-deductible plans, HSAs, and pricing health insurance according to people's experience.<sup>7</sup> They provide options for policy-makers, but do not provide tools for people.

Third, it promotes a different type of analytics for health. It diverges from the usual health care analytics that focus on business intelligence for the two Ps (providers and payers) by zeroing in on the health needs of the forgotten P, people. It is not about worshipping the “art of the possible” of information technology; it's about putting analytics to work to engage people to achieve their health potential. Thus, it opens up new territory for analytics professionals to provide value to their organizations and society and provides a framework and tools help them accomplish it.

**Let me describe the journey you will take with this book** by summarizing its key points and providing a road map and description of key destinations along the way. The first part of the summary

addresses the problem and background; the second part addresses solutions.

## Background

**People are coming to the realization**, supported by abundant research, that our own behaviors are far more consequential in determining our healthy longevity than the actions taken by others on our behalf.<sup>8</sup> We need to be drivers and not passengers, and our good health depends on it. We know we can do more, just like we do in other spheres of our life. We question why some of the things done in doctors' offices have to be done there. We go to box stores like Walmart and health stores like CVS Health to receive "retail" clinic care for common ailments. It is equivalent, quicker, more convenient, and cheaper. And while we are in these stores, we see an expanding display of high-quality products we can use to test and take care of ourselves. I classify these things under the heading of SOPrDiMoCa. (No, it is not a popular travel site in Italy or a seasonal coffee from Starbucks!) It is an acronym that stands for **Self-Oriented Prevention, Diagnosis, Monitoring, and Care**.

**These SOPrDiMoCa tools**, in combination with information available from other sources, such as labs, electronic health records (EHRs), and genomics companies, help people assess their own risk factors, sort out symptoms, monitor a wide variety of signs, symptoms, and life events, and adjust their own care. All of these tasks can be done effectively and safely in real time and in their own home. Not only are these products attractive, but they also save money by not using expensive and overly medicalized tests and treatments.

This becomes increasingly more important as people are exposed to more health care expenses because of significantly higher deductibles and health insurance restrictions such as limited networks. They are coming to realize, as Ben Franklin did centuries ago, that an ounce of prevention is worth a pound of cure. And that the effort, money, and pain involved in preventing illness is enormously less than what it takes to get back to health from a chronic disease.

**People have already adopted a more self-reliant role** in other aspects of their lives. They use data and tools to make their own decisions, and prefer to “do-it-yourself” (DIY) instead of relying on professionals to do their finances (e.g., online banking, electronic tax preparation and filing), travel (e.g., navigating directions, using online travel services), education (e.g., online coursework and degrees), shopping (e.g., buying online), and more. In many respects, technological advances have equipped and enabled people to take on these functions and have “changed cultural expectations regarding what people can learn, know, and do.”<sup>9</sup> The criticisms that people will not use data and tools to take a more active and decisive role in their lives have been debunked.

**What people want is to be healthy.** People are a tremendous resource to improve their health and care. The health care system should welcome this huge contribution, support it, and provide access to tools and information. This is not about a DIY movement in health care or about people becoming their own primary care provider. It is about people taking on the tasks that they can do best within the provider-person partnership for health. In addition to people having access to valuable over-the-counter products, providers and health plans need to have a formulary of apps and “adds” (sensors attached to smartphones) that they prescribe as a routine component of care.

**The five behaviors of everyday life are not medically mysterious.** The behaviors do not require a laboratory test or an MRI scan to determine that they are the cause of terrible chronic illnesses. They do not require elaborate treatments like chemotherapy, robotic surgery, or pharmaco-genomic medicines. In fact, in most cases they require very little medical attention. Doctors certainly can help by doing screenings and counseling and monitoring visits. However, according to Christensen et al., “following the diagnosis and treatment by physicians, in many instances physicians can’t add much additional value beyond teaching patients broad categories of do’s and don’ts.”<sup>10</sup>

**Health does not happen within the context of health care.** It happens within the context of each person’s life—their cultural, social, and economic frameworks modified by their values and priorities. People live with chronic conditions every day and spend over 5,000 waking hours a year in their company. Patients may see a doctor



four times a year for routine monitoring for a total of perhaps one hour a year. And, of course, all of us make decisions every day that define our health trajectory.

**Managing these chronic diseases requires vigilance.** Patients need to follow treatment plans, monitor signs and symptoms, and make adjustments. This requires experimentation because every person is different and many factors come into play. For example, it can be hard to determine what drives fluctuations in blood pressure and how to fine-tune treatments. Having weekly blood pressure measurements or a Holter monitor on for 48 hours provide a useful, but limited, window on patient experiences, relative to having real-time and relatively continuous monitoring of these signals. The same is true for patients with diabetes. It is important to track glucose levels, diet, exercise, and potential triggers, which is more manageable through continuous measurement, data integration, and insights from analytics. According to Christensen et al., “The (diabetic) patients and their families typically must distill from their own experience algorithms of diet and activity that minimize the severity of their symptoms. Patients with these behavior-intensive diseases can generally formulate better algorithms of care through trial and error than their physicians can.”<sup>11</sup>

**The personal health analytics resources available to people are abundant and growing.** There is a torrent of data available to people from sources such as genomics, sensors, health records, and the individuals’ own assessments. The data combine with other information technologies to make it useful, including connected devices to store and share the data; health social networks to democratize it, make meaning of it, and keep people engaged; and advanced computing power to provide insights, guidance, and support. This combination of features defines pchA. However, despite its potential, pchA is only in its infancy.

Technology can play a strong role in bringing about a person-centered health movement by perfecting better analytics designed for people. The business model has to change, however, from making us click to generate advertising revenues to understanding what makes us tick in order to make behavior changes stick. There are five key challenges: The first is to produce wise information in order to know the individual better than she knows herself. The shift is to move beyond

descriptive reporting and alerts to insight and guidance. The second challenge is to develop “digital hugs” in order to engage the individual emotionally. The shift is to move from superficial to meaningful interactions. The third challenge is radical intimacy in order to understand the individual fully. The shift is from mass customization to radical personalization. The fourth challenge is to develop riveting apps in order to equip the individual for change. The shift must change the orientation from novel, fun, and gimmicky applications to those that have value and are viewed as essential and become embedded in the person’s life. The final challenge is to produce coaching in order to partner with the individual. The shift must change from the relatively simple delivery of information to a dynamic, two-way conversation.

**In summary, investing in our health asset is fundamental to a long and healthy life.** Herophilos, a Greek physician from 300 B.C. said, “When health is absent, wisdom cannot reveal itself, art cannot manifest, strength cannot fight, wealth becomes useless, and intelligence cannot be applied.” The surest way to reap the benefits from our birth asset is to stay healthy and manage the five behaviors of everyday life. Increasingly, people are grabbing the baton, others are welcoming them as true partners in health, and powerful tools are emerging to equip them to be successful.

## Solutions

Two general areas of pchA solutions respond to the challenges to advance person-centered health. These include a Toolkit for People and an Opportunities Portfolio for Stakeholders.

### *Toolkit for People*

We must get more involved as an active participant in our health and there are supports to help us. The pchA toolkit is a comprehensive collection of tools, available today, which people can adopt and use on their own and with the help of family and health professionals. The tools allow people to know themselves much better. Knowledge is power—to understand where you stand in terms of health risks, what a good health horizon looks like, what the barriers are, and how

to overcome them. These tools help people believe in themselves and their capabilities to be the first line of defense to prevent and diminish the impact of illnesses.

The criteria for including a tool in the toolkit is that it must address four pchA technical cornerstones and the five analytics challenges, be cited by at least one of four expert reviews,<sup>12, 13, 14, 15</sup> or fill a gap in the pchA framework. The toolkit is not meant to be a listing of all tools available; rather, it provides indicative examples. (**Note:** I have had no contact with any of the organizations that produce the tools, received no compensation, and do not vouch for the tools beyond the representation of the tools by their developers and reviewers.)

The pchA toolkit is made up of four sections that encompass 11 unique topic folders, as shown in Figure I-1. Overall, there are 46 tools or resources. It is designed for people. Indeed, nearly all of the tools are self-administered, free, and do not require medical approvals.



**Figure I.1** Person-centered health analytics toolkit

### *Knowing Me*

The Knowing Me section includes folders on Health Status and Risks, Engagement and Self-Care, and Analytics Capabilities. Health Status and Risks includes five tools to understand where the person

stands in relation to health behaviors and other health risks, to assess a broader view of health in terms of well-being, and to (begin to) use genomic information for understanding health risks. Engagement and Self-Care includes three tools to understand the person's readiness, capabilities, and supports to be engaged in and practice self-care, including important measurements of patient activation, social risks, and personality. Analytics Capabilities addresses the person's capabilities to use analytics and includes three tools on health literacy, e-health literacy, and digital competencies.

This is the first time that these Knowing Me tools have been brought together expressly for people to use on their own. They are readily available, but not directly to people. They are marketed to health intermediaries for the purpose of managing people, improving care, and (mostly) reducing costs. These intermediaries *may* decide to use these tools and *may* decide to include people in the process. But, don't count on it. These tools are simply not high on their priority lists. The Knowing Me toolkit democratizes the information so that people can take ownership of it.

### *Protecting Health*

The Protecting Health area focuses on the four everyday behaviors of eating, sitting, smoking, and drinking (alcohol). There are two folders in Protecting Health, including Self-Monitoring Behaviors and Information for Staying Well. The Self-Monitoring Behaviors folder contains a few good examples of the many tools available that measure physical activity and weight with sensors and connected devices as well as with digitally enhanced logs that help people input their data into connected devices on foods eaten, cigarettes smoked, and drinks taken. All tools include the capacities to integrate data across devices, to communicate with peers and providers through mobile devices, and to present the data in compelling reports.

The other folder is Information for Staying Well. There is an enormous array of very good and not-so-good Internet websites that provide information on staying well and how-to guides on a variety of topics. Included are three good examples from the federal governments in the United States and the United Kingdom.

## *Minding Illness*

Minding Illness focuses on the fifth everyday behavior, taking medications, as well as on the self-monitoring of vital information for managing chronic diseases that account for the most years of life lost, that is, diabetes and heart disease. The most important modifiable risk factors for both of these disorders are high blood pressure, high fasting plasma glucose, and high cholesterol. (The other important risk factors include the four everyday behaviors addressed in Protecting Health.)

There are three folders in Minding Illness: Self-Monitoring Conditions/Meds, Self-Triage, and Peer Communities. The Self-Monitoring folder contains six tools. For diabetes, these include wireless blood glucose monitors connected to smartphones that communicate with providers and peers and provide data reporting and self-care guidance. For heart disease, there is one pchA tool for monitoring blood pressure. For Self-Monitoring Medications, there are innovative solutions, including prescription bottle covers that know when the container is opened and provide relentless alerts to take medications as directed, and reminder services that are radically tailored to the person's interests and preferences.

The second folder is Self-Triage. When people experience concerns about a turn in their health, such as pain, fever, a fall, or other symptoms, they want to know what it means and what to do next. Increasingly, people are using the Internet to get answers. Often the information is enough to allay concerns, avert a visit to the emergency room, and eliminate a worrisome wait until a doctor can see them. There are many general sites, but the best ones provide a platform for a conversation that allows for sharpening questions, resulting in a more precise formulation. Some of these sites rely on innovative technologies, including connected devices, computational analytics, crowdsourcing, social media, and elegantly simple user interfaces. One provides the capability to ask a question directly to doctors and get a response within a few minutes.

The third folder is Peer Communities. People are interested in knowing what patients like themselves are going through and what has worked for them. Many sites provide a platform for people to communicate with one another to share information and offer support. These

are especially important for people with rare disorders. Four of these sites are included in the Peer Communities file.

### *Managing Data*

The Managing Data area contains three folders, including Get Data, Store Data, and Protect Data and offers 13 tools. Although people generate much of their own data for pchA, important data are collected and stored by providers and health plans. People are entitled to it, but it can be difficult to get, especially if an EHR is not up and running well. The Get Data folder provides some tools to retrieve medical record information, including health care provider portals, such as “BlueButton” for U.S. Veterans and Medicare beneficiaries, and a retrieval service that does all of the work to get and store medical data. The surest way to assure one’s own access to medical records information is to select a doctor who uses an EHR. The file on Choosing Doctors provides some guidance and tools to sort this out.

The second folder, Store Data, addresses the need to store and organize all the newly found personal health data with four tools. People need to store different types of data for three general purposes, including emergencies, medical support, and insight to optimize health. There are three formats to storing the data, including paper, Personal Health Records (PHRs), and generic file management programs. PHRs are the ideal but have not gotten much traction with people because of the complexity of gathering and entering data from many sources. This may change as people see the value of widely available person-centered health data and weigh the new benefits with the costs.

Finally, there are privacy and security risks of being online generally, sharing information in social networks, and using specific pchA tools. Although the Health Insurance Portability and Accountability Act (HIPAA) protects medical data that are kept by providers, people need to initiate safeguards to protect their own personal health data. The third folder, Protect Data, contains five tools to achieve high competency levels of computer hygiene, manage the risks of disclosing too much on social networking sites, and address specific issues with mobile devices, apps, and PHRs.

## Opportunities Portfolio for Stakeholders

People need to be more self-reliant in managing their health, but also need the help of others. In this section on solutions, stakeholders and their roles are defined, barriers to their contributions to pchA are identified, and areas of opportunity for stakeholder action are proposed.

### *Stakeholders*

There are five key influential stakeholders that can affect and be affected by the advancement of pchA tools. It is important to achieve “alignment” with stakeholders by designing and implementing win-win solutions.

- **Health care providers:** Physicians make the vast majority of the decisions concerning the diagnosis and treatment of diseases. As such, they are the linchpin in deciding whether pchA tools are offered or prescribed and thereby regarded as a necessary component of routine medical care or, conversely, a novelty.
- **Health companies:** Health companies prosper by producing health. According to Christensen et al., “care for chronically ill patients needs to be overseen by entities that can profit from their patients’ wellness, rather than profit from their sickness.<sup>16</sup> Best practice examples include integrated delivery systems such as Kaiser Permanente and start-ups such as Omada Health.”<sup>17</sup>
- **Health insurers:** Health insurers exert their influence through their decisions on what is covered and how much they pay for products and services.
- **Government:** Government is a key stakeholder on a variety of fronts as a regulator, insurer, purchaser, provider, researcher, and jump-starter of innovations.
- **Technology companies:** This category includes organizations that invent and sell new products and services to improve health and health care, and includes digital health entrepreneurs, information technology companies, pharmaceutical companies, and device manufacturers.

## ***Barriers to Widespread Adoption of pchA***

There are three main channels for delivering pchA: Doctors can prescribe them, payers and health companies can provide them and people can buy them. The five key external barriers to widespread use of pchA, the five Ps, include physicians, payment, proof, pleasing the customer, and privacy:

- **Physicians:** Physicians rely on guidelines and evidence about the safety and effectiveness of innovations in their decisions about what to offer patients and so far the evidence supporting pchA tools is scant. Although pchA tools produce a wealth of data points for the continuous monitoring of conditions, their use must fit into the workflow, not add extra time to patient visits, and generate income. In addition, pchA tools need to have organizational vetting and approval from the C-suite, including medical, information, and legal officers.
- **Payment:** Payment and cost barriers include reimbursement (widespread medical adoption requires it), payment models (fee-for-service payments dampen the adoption of innovations), and consumer costs (patients are not accustomed to paying the list price of medical products).
- **Proof:** Evidence is required to demonstrate the value of pchA tools. There are different thresholds for evidence depending on function, including tools ordered by doctors, such as apps and adds—attached sensor devices—that monitor chronic conditions, tools that substitute for doctors (including self-diagnosis apps and adds), and tools that are nonmedical (including self-monitoring, connected devices for diet, activity, smoking, and taking medications).
- **Pleasing the customer:** Although a quarter of U.S. adults say they have used some sort of technology to track behaviors or symptoms,<sup>18</sup> most apps are discontinued after 30 days<sup>19</sup> and digital health platforms from big technology players, such as CarePass and Google Health, have bombed with consumers. These products have been slick and focused on making people click rather than on understanding what makes them sick and how to keep them well. Technology developers have misread

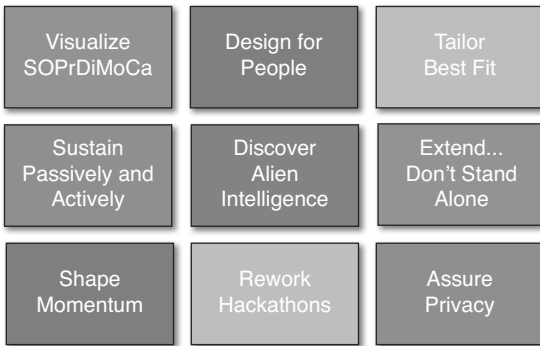


that people do not value the means to the end, including platforms, data aggregation, communications possibilities, and data reporting.

- **Privacy:** A persistent barrier to the proliferation of pchA is the lack of privacy protection. There are few legal protections for personal health data. Advertisers and data mongers scoop it up and resell it, and social media sites are breeding grounds for exposing intimate details to friends and enemies.

### Areas of Opportunity

There are nine areas included in the opportunity portfolio, as shown in Figure I.2.



**Figure I.2** Nine opportunity areas for stakeholders to advance pchA

### Visualize SOPrDiMoCa

SOPrDiMoCa, the acronym for **Self-Oriented Prevention, Diagnosis, Monitoring, and Care**, captures the scope of functions and locus of control of pchA and sets the stage for visualizing the path forward for pchA. The trend away from professionalism and centralization and toward simplicity, convenience, and a consumer-focused market is inevitable. The availability of home testing tools is expanding quickly. For example, OPTUM, a subsidiary of United Healthcare, provides an At-Home Kit for members for “biometrics.”<sup>20</sup> The

Public Health Foundation of India deploys the Swasthya Slate that can perform 33 tests, including blood pressure, glucose, hemoglobin, and ECG. It can also test for pregnancy, dengue, and malaria. It retails for Rs 25,000 (or about \$400 USD) and has been tested and approved for use by community health workers.<sup>21</sup> SimulConsult<sup>22</sup> is a diagnostic tool for physicians that ingests the complete body of literature for certain disorders along with information about the patient's condition to generate hypotheses with associated probabilities about what the patient may have. With more translation and technology, it will become a tool for people.

### ***Design for People***

It may be a truism, but evidently hard to attain, that technology developers need to understand the customer and respond with offerings they need, are willing to pay for, and are delighted to use. All too often, a true appreciation of the customer is glossed because of a predilection for mastering technology details, for example, a use case presentation that has 2 slides on customer needs followed by 20 on systems architecture. Multiple methods for designing-for-people include use cases, focus groups, usability labs, concurrent verbal protocols, and frequent prototyping.

### ***Tailor Best Fit***

Marketers know that “embracing radical personalization and putting individuals at the center of your marketing efforts is important because it can dramatically improve your conversion rate and increase the number of new, paying customers.”<sup>23</sup> The obvious parallel is to address how all the information known about an individual can be used to extend her healthy years of life. It's important to collect and use all relevant data to fine-tune predictive models, inform care processes, and manage one's own health. The fundamental inquiry is to understand how the data on the interactions among treatment and prevention approaches, apps and adds, incentives, genomics, and social supports, along with individuals' preferences, values, risks, and capabilities, all work together to produce the best, personalized, health outcomes.

## ***Sustain Passively and Actively***

Behavior change related to chronic conditions requires sticking with the program over a long period of time and pchA tools must keep people engaged with passive and active elements. One of the basic design features of apps and adds is to collect information passively because humans forget, get bored, and move on. Innovations like Google's contact lens to detect glucose levels,<sup>24</sup> Proteus's ingestible wafer to monitor prescription drug adherence,<sup>25</sup> and OMSignal's biometric-sensing clothing to measure vitals<sup>26</sup> are interesting examples. But, according to Gawande, "technology and incentive programs are not enough. Every change requires effort and the decision to make that effort is a social process."<sup>27</sup> Successful behavior change necessitates an active, ongoing, personal touch, trust, and guidance. Digital tools that provide "digital hugs and prods" are needed and may arise from future versions of Apple's Siri or Samantha, the voice behind the OS1 in the 2013 movie *Her*.

## ***Discover Alien Intelligence***

Artificial intelligence (AI) has matured and is ready to take center stage. For example, Eric Topol, in a preview for his new book, *The Patient Will See You Now: The Future of Medicine Is in Your Hands*,<sup>28</sup> states that "computers will replace physicians for many diagnostic tasks." AI will mine information stored in EHRs, research literature, and information on the experiences of many providers and patients to recommend potential diagnostic and treatment options to physicians, as is done with applications from the company Modernizing Medicine.<sup>29</sup> But, its most useful feature will be decidedly *unhuman*. It will not just automate and accelerate what our brains usually do. It will think differently. This is because artificial intelligence unerringly learns from all the data and the decisions it makes. It will add wisdom because it will offer a new perspective thereby becoming irresistible by engaging us with digital tools to improve our health.

## ***Extend...Don't Stand Alone***

pchA tools used for condition monitoring need to be regarded as extensions of usual medical care. For example, standard approaches to self-monitoring of glucose and high blood pressure constitutes acceptable clinical practice. The arguable point is that pchA tools extend and improve monitoring by incorporating new sensors, connected devices, and better data integration and reporting. Picking fertile spots to grow pchA tools as extensions of care is important. There are three good bets: (a) Integrated delivery systems focus on health and value and score the best in getting the patient job done of “help me to become healthy” and “help me to maintain my health” when compared with fee for service, national health plans, capitation in independent systems, capitation in integrated systems, and HSAs and HDI.<sup>30</sup> (b) Health management programs such as Healthways, Optum Health, and Omada Health also have business models to produce health. For example, Omada Health offers Prevent,<sup>31</sup> which is based on the NIH-sponsored Diabetes Prevention Program to help people with prediabetes avoid progressing toward type 2 diabetes. The program uses digital tracking tools for glucose monitoring, wireless scales and digital pedometers, personalized coaching, and social supports. (c) Medicare offers a variety of free medical benefits for chronic disease management. The addition of pchA tools would increase the value of these services by producing better outcomes at lower costs.

## ***Shape Momentum***

Innovations need many things to fall into place in order to challenge conventional wisdom and build momentum for recognition, adoption, and widespread diffusion. There are three promising spots for generating momentum: (a) The federal government can be a most influential stakeholder for the advancement of pchA. It has been instrumental in the adoption of EHRs through generous funding, standards setting, meaningful use performance measurement, and convening stakeholders for discussion, education, and building consensus. It can widen this focus and intensity to person-centered health analytics using similar means. (b) Multisector partnerships

among payers, researchers, employers, universities, pharmaceutical companies, and others can facilitate the adoption and diffusion of innovations. For example, health insurers are interested in value-based products and services and fund research to generate evidence. (c) It is hard to ignore the importance of venture funding in developing, researching, and marketing digital health products. For example, the company that has received the largest amount, between \$300 and \$400 million, is Proteus Digital Health, which is developing a line of products called *digital medicines*.<sup>32</sup>

### ***Rework Hackathons***

Hackathons are characterized as “weekend events where coders, data geeks, and designers conspire to build software solutions in just 48 hours”<sup>33</sup> based on the assumption that the diversity of talent and the ethos of a creative pressure cooker will create something special. But, it all depends on who is in the cooker. Hackathons have been useful for addressing very specific technical problems like taking something apart and rebuilding it, such as a line of code or a set of data.<sup>34</sup> But, in order to achieve breakthroughs in personal health technologies, health care experts and patients need to be at the table. *Shark Tank* is an ABC TV show that features entrepreneurs pitching business ideas to a panel of investors (the “sharks”). If the sharks like what they hear, then they offer a deal. Sarah Krug, past president of the Society for Participatory Medicine, thinks patients should be on the panel in what she calls The Patient Shark Tank®.<sup>35</sup> The premise is that patients should be the thought leaders who influence innovations that “incorporate the voice of patient into the design, development, or enhancement of technology.” The pitch for such involvement has been made to investors and time will tell if they take the bait.

### ***Assure Privacy***

Assuring privacy protections is critical for the advancement of pchA. There are two general approaches: The industry can manage itself through a code of conduct or the government can step in with regulations. There has been a lot of talk in Congress and from

the Obama administration about privacy. A number of reports have been issued such as the Federal Trade Commission's *Data Brokers: A Call for Transparency and Accountability*, which included a clear set of recommendations,<sup>36</sup> and a few bills have circulated, including one from Senator Al Franken, chair of the Judiciary Subcommittee on Privacy, Technology, and the Law, which addresses the "growing problem of "stalking apps."<sup>37</sup> However, Congressional action has been meager. And that pleases the data aggregator and marketing industries just fine. Tony Hadley, senior vice president for Experian, voiced the usual industry refrain that, "Industry standards, not legislation or regulation, should determine how companies collect and use information about Internet users for marketing purposes."<sup>38</sup> Some have recommended that a "code of conduct" be developed by the industry to define standards to address patient privacy and confidentiality concerns.<sup>39</sup> One of the major industry players, Acxiom, has initiated programs to address this, including "Data Privacy Day," which is "celebrated every year on January 28"<sup>40</sup> and a website, AboutTheData.com, that "provides answers to questions about the data that fuels marketing and helps ensure you see offers on things that mean the most to you."<sup>41</sup> Clearly, privacy protection issues will be on the back, hot, burner for a while to come.

### ***Welcome Aboard!***

The main focus of *Using Person-Centered Analytics to Live Longer* is to empower, enable, and equip people to take a more active and self-reliant role in managing five behaviors of everyday life to maximize their chances for a long and healthy life. Analytics can help, and to that end, a guidebook of 46 pchA tools is offered to help people navigate the journey. People cannot do it alone; they need the help of others. Stakeholders can have a significant influence over the adoption and diffusion of innovations. In order for them to align with change, rather than maintain the status quo, they need to agree with the cause and see clear benefits to doing business differently. To that end, barriers are identified and a portfolio of nine opportunities is offered for stakeholders to improve peoples' health and their own bottom line.

Please join me on this journey to understand and apply person-centered health analytics by diving into the details in the next 15 chapters.

Note that person-centered health analytics is a rapidly evolving field. New products are being developed and released, evidence on safety and effectiveness is emerging, experiences with using the tools are accumulating, and stakeholders are weighing in and taking actions. Readers can turn to my blog, [dwrightmccneill.blogspot.com](http://dwrightmccneill.blogspot.com), to get regular updates on developments in the field.

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# 1

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## It's About Health Outcomes!

While the United States continues to argue about whether and how to provide all of its citizens with health insurance and how to contain the high costs of health care, it has lost sight of the purpose of it all. The purpose of the vast \$2.8 trillion health care industry, the most expensive by far of all countries in the world, is to produce better health for all Americans. It is failing and it is getting worse.

### Health Care's Veiled Purpose

Why has the United States taken its eyes off the prize of better health? Part of the reason is that many Americans believe the slogans from some political pundits who say that the American health care system is the best in the world and should not be touched with reforms like the Affordable Care Act (ACA). “When Italian Prime Minister Silvio Berlusconi needed heart surgery, he didn’t go to an Italian hospital...He had his surgery at the Cleveland Clinic in Ohio... because the U.S. health care system still provides the highest quality care in the world,” proclaimed Michael Tanner of the CATO Institute.<sup>1</sup> Of course, a few anecdotes about the special treatment provided to world leaders does not square with the body of evidence that paints a different picture about how well the American health care system fares for all its citizens. Cathy Schoen, senior vice president at the Commonwealth Fund, which studies the performance of the U.S. health care system as compared with other developed nations, says “We (the United States) spend a lot more, our access is often worse, we face more medical debt, and our health outcomes are often worse.”<sup>2</sup>

Another reason why we do not have a laser focus on health outcomes may be the mistaken belief that outcomes are not measurable. As we will see shortly, the measures are credible, the data are compelling and convergent, and the interpretations are reasonably clear.

The harder part about outcomes is not so much in the measurement, but in the doing. The doing involves deciding who to hold accountable and collaborating across health, medical, and social systems—and with the people served—to set a vision and goals and actually make improvements happen. Outcomes are shaped by many factors, including social, behavioral, genetic, environmental, and health care delivery, with multiple systems making specific contributions based on their unique missions. However, the defining feature of the U.S. health care “system” is its fragmentation and lack of coordination among its stakeholders within health care and (even worse) across systems with other co-producers of health, including the public health system, social services, civic communities, and people themselves. Integration is hard and messy and has been perennially elusive. Who dares to step to the plate? In the meantime, we concentrate on other things besides outcomes, such as costs, driven by other purposes.

The nation spends much more time worrying about saving dollars than about saving lives. Dollars are easier to measure. Even the value of a life is measured in dollars. According to economists, it is valued at about \$71,000 per year of life.<sup>3</sup> In the United States, the policy and business calculus is often focused on how to save money while not damaging the quality of care. At its best, it is about getting more value for money spent. However, all too often, the achievement of better quality and outcomes through known approaches is not attempted because it costs too much, is not rewarded financially, or is hard to accomplish successfully because of an ingrained status quo culture and other implementation challenges.

Economists fixate on expenditures and are very influential in framing the major debates about health care. Prominent economists have projected that the tab for health care services will be almost double and reach \$5 trillion in 2022 (just seven years away) if historical growth trends continue.<sup>4</sup> They warn that health care would pose a “crushing burden” on society and that “health care profligacy, and the

strains that such a situation imposes on society, could fundamentally undermine the economic and social well-being of the United States over the long term.”<sup>5</sup> Got your attention? This is not a new Armageddon theme from the “dismal profession.”

However, the future may not be so bleak. It is not at all clear that the historical growth trends will reemerge following the recent period of several years when health care spending growth has been at historical lows and lower than the growth of the gross domestic product (GDP). Federal estimates for the long-term growth in Medicare and Medicaid have been ratcheted down significantly. And, growth in health care expenditures may not be bad if it actually produced good health and better productivity and thereby increased GDP! However, at the present time, too much, perhaps a third, of the health care tab is pure waste. And, unfortunately, the health outcomes produced are getting worse.

### ***Measuring Health Outcomes***

The most recent study on the health of the U.S. population was published in *JAMA* in July 2013 and authored by over 125 research collaborators around the world. The purpose of the study was to measure the burden of diseases, injuries, and leading risk factors in the United States from 1990 to 2010 and to compare these measurements with those of the 34 countries in the Organisation for Economic Cooperation and Development (OECD) countries.<sup>6</sup> The good news is that between 1990 and 2010, the United States made progress in improving health. The bad news is that its improvements were not as great as other countries and the United States is losing ground to most other countries in securing the best health for its citizens.

The headline from the study is that the United States ranks twenty-seventh in the age-standardized death rate behind countries having a significantly lower GDP and health expenditures per capita, including Chile, Portugal, Slovenia, and South Korea. This puts the United States at the lowest quartile among the 35 countries. Further, the rank is getting worse. It changed from eighteenth to twenty-seventh in these 20 years.

Overall, mortality rates are a useful, but gross, measure. More refined and meaningful measures provided in the report include (1) years of life lost due to premature mortality (YLL)\*, (2) years lived with disability (YLD), and (3) healthy life expectancy (HALE). On two of these measures, YLL and HALE, the United States dropped significantly in the rankings to twenty-eighth (see Figure 1.1) and twenty-sixth, respectively. The YLD also dropped, but not as much (from fifth to sixth).



**Figure 1.1** The United States ranks 28 among 34 OECD countries on years of life lost due to premature mortality.

Adapted from U.S. Burden of Disease Collaborators, 2013.

\* The YLL measure is computed by multiplying the number of deaths in each age group by a reference life expectancy at that age for each disease category. For example, if a person dies at 45 from a heart attack and the benchmark life expectancy is 85, then the YLL is 40 years.

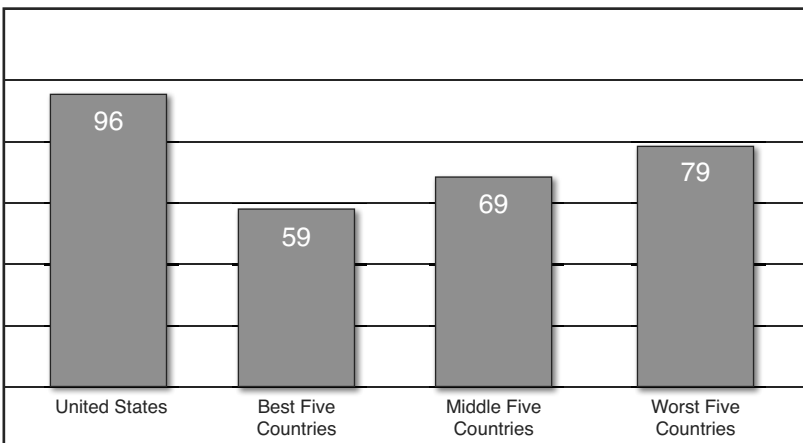
The authors also compared the ranks of YLLs for 25 medical conditions across the 34 countries. Overall, the United States scores worse than the mean rank of the countries for a majority (15) of the conditions, at the mean for 9 conditions, and better than the mean for only one condition (stroke). For example, the United States scores in the lowest decile of ranks, that is, a rank of 31 or worse out of 34, for the following conditions: interpersonal violence, road injuries, chronic obstructive pulmonary disease, diabetes, drug use disorders, Alzheimer's disease, poisonings, cardiomyopathy, and chronic kidney disease.

Similarly, a report from the National Academy of Sciences and The Institute of Medicine, "U.S. Health in International Perspective: Shorter Lives, Poorer Health,"<sup>7</sup> demonstrates that the United States fares the *worst* among 17 wealthy OECD nations on nine health domains, most of which align with those in the *JAMA* report. They state that deaths that occur before age 50 are responsible for about two thirds of the difference in life expectancy between males in the United States and peer countries, and about one third of the difference for females. This has been a long-standing finding. Since 1980, the people of the United States have had the first or second lowest probability of surviving to age 50 among the 17 peer countries. The conditions that account for this difference include chronic disease and perinatal conditions, but over 50% are not defined as a usual medical disorder and include violence and accidents. The authors refer to a health-wealth paradox that is a "pervasive disadvantage that affects everyone (in the US), and it has not been improving."<sup>8</sup>

Convergent data on the low rank of the United States on health and wellness measures comes from the Social Progress Index.<sup>9</sup> The index addresses three overarching domains that cover basic human needs, well-being, and opportunity. One of the indicators included in the well-being domain is health and wellness. The indicator is composed of measures of life expectancy, premature death from chronic diseases, obesity, deaths attributable to outdoor pollution, and suicide. The health and wellness score for the United States is 73.61, which places it at a rank of 70 among the 132 countries included in the analysis. The usual suspects have the highest ranks, including Japan, European countries, Australia, Iceland, and (not so usual) Peru. Countries that scored in the low 70 rankings alongside the United

States included the Dominican Republic, Togo, Kenya, Ghana, Cuba, Nepal, Slovakia, and Mali. Russia, Ukraine, and Kazakhstan had the worst ranks. Further, of the 12 components of the Social Progress Index, covering diverse areas, including personal safety, ecosystem sustainability, tolerance, and inclusion and access to education, the lowest rank for the United States was for health and wellness.

There are multiple causes for the worsening of health outcomes in the United States. One that requires close examination is the performance of the delivery system. One good indicator is a measure called premature mortality amenable to health care. Included in this mortality rate are diseases with a well-known clinical understanding of its prevention and treatment, including ischemic heart disease, diabetes, stroke, and bacterial infections. In other words, the science is very clear on what needs to be done for these diseases and the premature mortality rate is an important indicator of the success of the health care system in executing on the science. Figure 1.2, adapted from the Commonwealth Fund’s *National Scorecard on U.S. Health System Performance 2011*,<sup>10</sup> compares the mortality amenable to health care rate across 17 wealthy countries. The U.S. rate of 96 deaths per 100,000 lives is almost 40% higher than that of the best performing five countries, including France, Australia, Italy, Japan, and Sweden at 59 deaths per 100,000. The United States is almost twice as high as the country with the lowest rate, France, at 55 deaths.



**Figure 1.2** Mortality amenable to health care: premature death rate per 100,000

Adapted from the Commonwealth Fund, 2011.

This “voltage drop” from what is known to what is actually practiced was first documented in a now-classic study authored by Elizabeth McGlynn and her colleagues at the RAND Corporation, *The Quality of Health Care Delivered to Adults in the U.S.*,<sup>11</sup> over ten years ago. Their research addressed the clinical adherence to recommended processes of care for 30 acute and chronic illnesses, as well as preventive care, with 439 indicators. Overall, the results showed that patients received recommended care about 55% of the time. They concluded that these deficits in the provision of recommended care “pose serious threats to the health of the American people.”<sup>12</sup>

In summary, it is important to underscore the severity of these findings. The health of the American population, as measured by living a long and healthy life, is worse than most other developed countries and getting worse. The data has been clear for years. Yet, the statistic of ranking twenty-eighth seems to elicit a collective shrug expressing “that’s the way it is” and nothing can be done about it. It has a similar ring to climate change—the problem is undeniable, it has to be fixed, and we (mostly) know how to do it.

## **The Uneasy Business of Health Outcomes**

Despite the substantial missed opportunities accruing from a lack of focus on health outcomes, the business case for doing so may not be obvious, and other significant pressures drown out the need to change business-as-usual.

### ***Missed Opportunities***

There are many areas for improvements in prevention and clinical outcomes to produce a long and healthy life. And saving lives can lead to saving dollars and/or creating value. But, it is clear that the businesses of health, including health care providers, payers, and life science companies, are not betting the business on it. Let’s look at a few big opportunity areas:

- If the United States achieved the best (lowest) premature death rate among OECD countries, it would save 36 million years

of life per year. The monetized value of the lives lost is \$2.6 trillion. This is nearly equivalent to annual health care expenditures of \$2.8 trillion.

- If U.S. health care were to use Big Data creatively and effectively to drive outcomes and quality, the sector, according to McKinsey & Company, could create more than \$200 billion in *value* every year mostly in the areas of comparative clinical effectiveness and clinical decision support.<sup>13</sup>
- If patients with cancer, heart disease, and diabetes received more personalized care, including computer-aided differential diagnosis, connected health, sensors for remote monitoring, tailored treatments, and better communications within health care and to patients, at least 20% of them would live at least two years longer.<sup>14</sup> Over 40 million Americans have these diseases.<sup>15</sup> The extra years of life has a *value* of \$800 billion for this cohort.

The benefits of these outcomes, especially the extended years of life, accrue to the patients who receive the care. But, people do not write a thank you card and a check to anybody for the value of extended life. No money changes hands. But, if it did, it might change the incentives of health care businesses. The predominant payment system is based on fee-for-service and designed to reward providers based on the quantity of services, not on the quality or the outcomes. This system can also lead to (un)intended consequences, including overtreatment. What we need is a fee-for-outcomes system that does not induce excessive services, but excessive years of life!

Is there a business case for actually producing longer and healthier lives? Could a company differentiate itself by demonstrating that it does a better job than its competitors? We do not see evidenced-based research or advertising that says, “Our health plan members live five years longer” or “Our heart attack patients live longer with a better well-being and we can prove it.” Why not? The data is certainly available, but the results may be equivocal. Perhaps marketing based on declarations about “the country’s best doctors and hospitals,” however conveniently defined, gets more traction on driving market share.

Although pay-for-outcomes systems have been espoused for decades, the present approximations include pay-for-performance



and capitation. Pay-for-performance programs provide a modest bump in cash for providers that produce services of high quality. Capitation or global payment plans involve a prepaid payment for the care of individuals over a period of time. Under these plans, when the population of individuals in the plan use less services than those that are priced into the premium, the health insurance plan or provider group makes a profit. The theory is that providers would be unshackled from the fee-for-service system and be driven by a business model that provides the right mix of prevention and care that results in fewer services, at less cost, and, maybe, better outcomes. The theory is sound that these approaches should work, but in the real world the adoption of pay-for-performance systems has been low or the potency of the incentives has been insufficient to have a significant impact. Global payment schemes have been discussed for quite some time, are getting more traction, but have not achieved much scale.

For the most part, it is business as usual concerning financial incentives to produce better health outcomes in the form of more years of life. For example, health insurers would make a profit of an average of 5% to 10% on the extra years of premiums charged, which would amount to about \$500 per individual per year. Providers would receive revenues for the extra services provided for the extended years of life and perhaps a small pay-for-performance bonus for providing better care. Life science companies would receive revenues for selling more prescription drugs. But none of these revenues would come remotely close to the value of extended healthy years of life for the people receiving them and the society at large that benefits from more productivity and well-being among its citizens.

We put a high value on our healthy years of life. Our health is a very intimate thing. Without good health, “we have nothing,” as the old saying goes. It is difficult to have a satisfying personal and a professional life without good health. We think it is “priceless,” but let’s get specific. At birth, we are given the gift of life. This gift amounts to an average of 79 years for a person born in 2012 with a lifetime value of \$5,530,000. For 99.9% of us, it is the most important asset we will ever have.

The health care industry is unique among industries. Its value proposition is to relieve suffering and make people feel better. And there is an implied sacred trust that doctors and hospitals will always

act on our behalf with a clarity of purpose to do everything they can to heal us. But, unfortunately, this is not always the case. There are too many wasteful tests; too many deaths and injuries resulting from medical errors; too much marketing to induce people to buy drugs, devices, and procedures they do not need; and too much lobbying to maintain the status quo despite the possible gains for patients from disruptive innovations. Quite frankly, all too often, the health outcomes for people take a backseat to the business needs of the health care industry.

### ***New Pressures on the Business and Analytics***

The business of health care has a commanding influence on the economy and people's lives. Expenditures in 2012 were \$2.8 trillion, representing 18% of the economy, and employing over 14 million people.<sup>16</sup> Hospitals are often the largest employer in a community and a state. The size of the largest health care businesses is huge. For example, Kaiser Permanente, an integrated delivery system and health insurance plan, has almost 9 million members/customers, 173,000 employees, 16,658 physicians, 37 hospitals, 611 medical offices, and operating revenues close to \$50 billion in 2011.<sup>17</sup> The largest health insurance company is United Healthcare Group with over \$100 billion in revenues.<sup>18</sup> The largest life sciences company is Pfizer at \$50 billion in total revenues.<sup>19</sup> And profits are good from an industry perspective. The industry is ranked fourteenth in profitability among 35 industries. Profit growth has been about 8%.<sup>20</sup> Share prices for four of the major insurance companies—Aetna, Cigna, Humana, and UnitedHealth—have more than doubled since 2012.<sup>21</sup>

But the business of health is under pressure. It might be flatlining. According to U.S. government actuaries, real spending for health care increased a scant 0.8% in 2012, slightly less than the real gross domestic product (GDP) per capita. This follows a few years of growth below the GDP. In contrast, since 1960, health care spending has increased an average of 2.3 percentage points more than GDP growth.<sup>22</sup> Convergent data from the Bureau of Labor Statistics shows a drop in health care employment in December 2013, which is the second time this has happened in 23 years.<sup>23</sup> Visits to doctors across the United States are dropping on the order of 7.6%.<sup>24</sup> And overall

prescription drug revenues are declining.<sup>25</sup> The slowdown may be just a blip in the relentless upward trend in expenditures. But, it may also signal other fundamental shifts, as discussed below.

In addition to the revenue pressures resulting from the flatlining of health care utilization, there are unrelenting compliance requirements that providers and payers need to respond to, ranging from meaningful use, to performance metrics for readmissions, to consumer engagement and more, as well as numerous regulations under the Affordable Care Act. Many of the compliance requirements have an analytics component that strains existing legacy information systems. The first priority of many provider IT departments is to digitize a wide variety of transactions, most especially the electronic health record, in order to keep up with compliance reporting. Often, the metrics that are adopted, as above, are the ones required by CMS and others. Therefore, branching out into other analytics, such as outcomes measurement, may seem less emergent (although important) and not worth the time, effort, and cost.

Health care analytics tends to focus on business intelligence; that is, providing information to help the business succeed (for example, revenue enhancement, reduction of operational costs, fraud detection, process improvements, compliance requirements, and so on). It has not concentrated on health intelligence. There are understandable reasons for this, not the least of which is the pressure on businesses to make a profit and on analytics to digitize the business and provide information for “today’s needs,” such as compliance.<sup>26</sup>

Analytics has a lot to offer in the form of health intelligence. It has the capability. Indeed, it has an impressive toolkit, an expanding availability of Big Data sources, and impressive advances in information technology and computational powers. The demand is great in this area, for example, to improve the care for people with chronic diseases. And there is great opportunity for analytics to strut its stuff and provide informational insights for competitive breakthroughs in these health domains.<sup>27</sup> But, like horses in a race, it has its blinders on and is driven to win the business race. In so doing, all the air is sucked out of the analytics enterprise and little is left over to support improvements in outcomes.

Change is particularly hard in health care. Nobody wants to rock the boat in a turbulent environment. Every change has consequences.

The biggest obstacle has always been the entrenched way of doing business in the health care industry. As Uwe Reinhardt, the Princeton health policy sage, observes, “Given that every dollar of health care spending is someone’s health care income...there must exist a surreptitious political constituency that promotes...waste.”<sup>28</sup>

People may rise up and ask, “Why aren’t my outcomes getting better?” and “Why is it that the self-interests of the business of health care are superordinate to earnest consideration of my good health?” An accelerator of this awareness and outrage may be the vastly increased copayments required of consumers from the new generation of health insurance plans. Bronze and silver plans, with \$2,500 deductibles as the norm, will make people think about the price and value of the care they receive. It may curb unnecessary use on the demand side (although research has shown that high copayments reduce use of both good and bad services). People may be shocked and outraged at how much they have to pay when they get sick. And, they may ask other questions and want answers about uncoordinated care, excessive testing, emergency room visits that take many hours, inconsistent messages from different providers on the right course of treatment, routine medical errors while in the hospital, the hassle involved in simply signing up for health care coverage, and why their medical networks have been narrowed and their doctors squeezed out.

## **Occupy Health Care**

Paul Keckly suggests that “a massive, predictable pushback directed at the US healthcare system may result in an Occupy Healthcare movement” similar to the Occupy Wall Street movement.<sup>29</sup>

Americans are questioning the value of long-standing institutions and, increasingly, are responding by either avoiding them or trying to upend them. And so it is, he says, with health care.

## ***Rebuilding the System***

Are Americans satisfied with their health care system? The answer is “not very” when compared with other countries. In a survey by the

Commonwealth Fund in 2013 of the general populations in 11 countries—Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States—responders were asked whether their country's health system (a) “works well, needs minor changes,” (b) “needs fundamental changes,” or (c) “needs to be completely rebuilt.”<sup>30</sup> Responders in the United States were much more likely than their counterparts in other countries to endorse major reforms. Only a quarter of Americans said the U.S. system worked well enough to need only minor changes, while almost half said it required “fundamental changes,” and another 27% said it should be completely rebuilt. Compared with other countries on the percentage of responders who said it should be completely rebuilt, the United States is more than three times that of the average of all the ten countries, almost seven times that of the United Kingdom, and more than twice that of the country closest to it (Norway). The survey indicated frustrations with the American way of health care that contribute to the preference to rebuild the system, which mostly had to do with cost and complexity. Americans were significantly more likely than their counterparts in other countries to forgo care because of cost, to have difficulty paying for care even when insured, and to encounter time-consuming insurance complexity.

### ***Generation Unmoored***

The Millennial Generation, the 18–34 year segment of the U.S. population, is about 80 million strong and is at the leading edge of this avoid-and-replace attitude. The Pew Research Center surveys the different generations of the U.S. population on their attitudes, beliefs, values, and actions. Its 2014 report focuses on how the Millennials compare with other generations, including Generation X, Baby Boomers, and Silent and the implications on how they may change the status quo of established institutions and facilitate the emergence of new ones.<sup>31</sup> For comparison, the ages of the other generations are Generation X, 34–49; Baby Boomers, 50–68; and Silent, 69–86.

One of the major observations of the report is that Millennials are “unmoored” from important institutions. For example, 50% have no political affiliation (compared with 37% of Boomers), 29% are religiously unaffiliated (compared with 16% of Boomers), and 26%

are unmarried between the ages of 18 and 32 (compared with 48% of Boomers). Another major finding is that Millennials are relatively untrusting of people and institutions. Only 19% say that most people can be trusted, half the percentage of Boomers. Millennials are not faring well economically, due in no small part to the Great Recession. They are the first generation to have higher levels of student loan debt, poverty and unemployment, and lower levels of wealth and personal income than their two immediate predecessor generations had at the same stage of their life cycles. Finally, they are connected to “friends” on social media and are avid users of digital devices. Eighty-one percent of Millennials are on Facebook, where their generation’s median friend count is 250, far higher than that of older age groups.

Their rejection of mainstay institutions, lower levels of trust, poorer economic status, and their preference for digital communications among peers may have profound implications for the institutions of health care. According to Keckley, they expect service 24/7, delivered through multiple devices, anywhere they prefer to be, and responsive to their expectation for convenience and efficiency. They, like responders to the Commonwealth Fund survey, are undoubtedly frustrated by the lack of coordination of services, by “paper” rather than digital, and by paternalistic approaches to their health care and insurance. They want health care data on prices and quality to be readily available and transparent just like it is in other industries, including retail and banking. They have little regard for bureaucratic inefficiencies and have a negative view of the difficulties in getting insurance and getting their own data from medical records. They question the necessity and value of the services proposed by doctors given their financial situation and the steep out-of-pocket expenses they face with high-deductible insurance plans. They want to know the evidence about what works and what does not. They do not accept the adage that “doctor knows best” and are likely to flip the paradigm from “My health is up to my doctor” to “my health is my responsibility and I need to have the tools to manage it.” They may have a jaundiced view of excessive profits, unless it is clearly earned through dedication to purpose and the delivery of good results. And they want the arguing in health care to stop between insurers and providers, members of Congress, and other warring factions.

A new insurance plan, founded by two Millennials who think they know what their peers want (as well as the rest of us), is called Oscar. It is taking on the staid business of health insurance by providing an easier customer experience, a well-designed website, unlimited phone calls with physicians, and price transparency. One of the founders, Joshua Kushner, 28, thought there has to be a better way when he opened up a bill from his insurer and could not understand a thing.<sup>32</sup> The infamous Explanation of Benefits (EOB) letters are anything but explanatory and seemingly intended to obfuscate the important information on prices and payments that consumers need. The phone calls with physicians can include a quick diagnosis and prescription for common ailments and a discussion about whether to go to the ER after a fall. Oscar also provides an estimate on what the out-of-pocket prices would be for procedures and specialists. This addresses one of the last bastions of secrecy. It is well known that common procedures, such as an MRI, x-ray, and colonoscopy, can have prices that vary threefold or more depending on the provider and payer agreements.<sup>33</sup> And neither the provider nor payer seems to “get it” that people deserve this information and do not like that it is hidden. Mr. Kushner says, “What we’re doing here—showing prices—should have been done 20 years ago.”<sup>34</sup>

### ***Taking Off the White Coat***

So, Millennials and many of the rest of us are asking doctors to please take off those white coats. For example, my son is a Millennial and his encounters with the health care system have made him angry and skeptical. His expectation of a hospital, given his experiences, is that it *will* make mistakes to his detriment. Most of his experiences are with the emergency room in a major city at a teaching hospital. He does not understand why he had to wait to get treatment for a stomach ache in the ER for eight hours, but then did get treatment after his appendix burst. This resulted in surgery, staying in the hospital for ten days, with a tube down his throat, no food, and a bill for \$60,000. He does not understand why another visit to the ER ended up with workups involving four sequential interns and residents asking the same questions, including whether he had had a tetanus shot. When the real doctor finally emerged after four hours, he asked the

same questions. My son wondered why they had not communicated among themselves. He could see his electronic medical record, but wondered if he was the only person who looked at it. He believes that he is just as likely to get worse, as to get better, in a hospital.

This is not an idiosyncratic story. It has probably happened to you or somebody in your family. It even happens to world-renown experts in the field of health care. Read or watch Don Berwick's account, *Escape Fire*, of his wife's hospital experience, including medication errors, disagreements among doctors, extreme lateness in getting medications needed, and oh-so-non-patient-centered care.<sup>35</sup>

It is, perhaps, understandable that mistakes can be made in health care. Don Berwick says, "It's not bad people; it's bad systems." Health care is complex, not well coordinated, under pressure financially, and the list goes on. But, there is something else going on with the culture of medicine. Eric Topol, in his book *The Creative Destruction of Medicine*,<sup>36</sup> refers to a new era where physicians are no longer regarded as "high priests, holding all the knowledge and expertise and not to be challenged or questioned by the lowly consumer patient" and that "doctor knows best" will no longer be a pervasive sentiment shared by patients and especially physicians." He insists that the digitization of the human body along with other cultural shifts will democratize medicine and that medicine will no longer be practiced in a paternalistic way." However, he admits that "If there were ever a group defined by lacking plasticity,\* it would first apply to doctors."<sup>37</sup>

Many of us want to take responsibility for our health and do not want to have important decisions made "about us, without us." But physicians as a profession have resisted reasonable approaches that allow patients and families to make decisions about their own care. Physicians have resisted DIY (do-it-yourself) testing and treatment on many fronts. In the past, they have resisted home-based, over-the-counter, pregnancy tests, HIV tests, genetic testing, and automated external defibrillators (AED), all of which have provided good benefits with little risks to patients. Even today, the battle continues on whether patients can have access to their lab reports without first going to the physician.<sup>38</sup>

\*Plasticity. Noun. The quality of being able to be molded into different shapes.



And the medicalization walls continue to come down. In response to the heroin epidemic and the related surge in deaths due to overdose, people can now administer a very effective treatment on their own, without physician oversight, to save lives. An amazing handheld device, Evzio, delivers a single dose of naloxone, a medication that effectively reverses the potentially lethal effects of a heroin overdose.<sup>39</sup> It is similar in size and simplicity to an EpiPen, which is used to stop life-threatening allergic reactions including anaphylactic shock. It is the size of a pen and can be tucked into a pocket. Evzio is designed with the consumer in mind and even provides audio instructions on how to deliver the medication. The needle is retractable and not seen by the person using it.

Clearly, the potential is great for DIY innovations to save lives. Another potential use is thrombolytic therapy to break up blood clots and save lives for people with heart attacks. Time is critically important and administration of the drug as early as possible is important for survival and good recovery. The question is: To what extent should people's home-based first-aid kits expand beyond Neosporin and Band-Aids and include a variety of reliable and easy-to-use, self-administered treatments? And to what extent will physicians oppose them?

People have other questions. Why is it not possible to communicate with their doctors via e-mail and why is an office visit needed when many concerns can be addressed over the phone or by e-mail, in just a matter of minutes?

So, doctors need to take off their white coats, except when they are in surgery, drawing blood, or getting stained in other ways, and "get down" and establish relationships with patients that include listening, shared decision making, respect for patient wishes, and trust that they can be partners to take care of themselves, including reading a lab report and performing a test without their oversight.

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