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Consumer Informatics and Digital Health

Solutions for Health and Health Care

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Chapter 1

Promoting Consumer Engagement in Health and Health Care



Margo Edmunds

Introduction: Converging Influences and Larger Trends

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

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

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

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

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

Health Information Technology Policy and Quality of Care

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

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

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

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

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

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

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

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

The Democratization of Health Care

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

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

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

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

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



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

The Consumer Movement and Person-Centered Care

Consumer Informatics

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

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

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

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

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

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

Term	Google results on May 4, 2017
Digital health	148,000,000
Consumer Health IT	16,900,000
Connected health	16,000,000
e-Patient	9,040,000
e-Health	8,550,000
i-Health	4,910,000
Telehealth	3,870,000
Health IT	3,250,000
mHealth	2,270,000
Consumer informatics	907,000

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

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

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

Telehealth and Telemedicine

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

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

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

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

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

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

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

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

Self-Care, Patient Education, and Behavior Change

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

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

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

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

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

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

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

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

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

Digital Health: Tools of Empowerment

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Population Health: Determinants of Health

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



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

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

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

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

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

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

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

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



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

Community Engagement

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

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

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

International Ratings and Rankings

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

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

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

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

Emerging Trends and Future Opportunities: What Do People Want?

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

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

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

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

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

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

Summary and Conclusions

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

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

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

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