# Chapter 4. Strategic Factors in Realizing the Potential of e-Health

## Introduction

This chapter looks at the forces that are connecting consumers and e-health tools and creating a dynamic e-health marketplace. It depicts an e-health arena that is evolving in response to cultural and technological trends, market and health system forces, and policy initiatives. It also identifies the limits of the current e-health market to coordinate e-health tool development, evaluation, and dissemination; generate sustainable business models for e-health tools; and provide strong privacy protections and quality assurance to nurture public trust. These activities are generally beyond the market's capacity to address on its own because they require changes and investments for which there is no immediate or direct return on investment for individual stakeholders. Given the public interest in and policy commitment to universal access to broadband technologies and electronic health records noted in Chapter 1, the public sector has the ultimate responsibility for ensuring these limitations are addressed.

Government coordination of efforts to realize the public health potential of e-health tools could be synergistic with existing public-sector programs and could help advance a number of important policy goals, including eliminating health disparities and supporting consumers in taking more responsibility for their health. Government cannot achieve these changes alone, however; it needs to join forces with the many stakeholders profiled in this chapter to design and carry out strategies from which every participant can derive appropriate benefits.

## Signs of Dynamism

Consumer e-health is part of the broad cultural shift toward Internet and technology use, such as portable music devices, cell phones, instant messaging, and interactive voice-response systems, as a normal part of everyday life. At the end of 2004, approximately 70 million Americans used the Internet on a typical day for activities as varied as banking, shopping, real estate transactions, research, entertainment, self-expression, and voting; the Internet is "the new normal" (Rainie and Horrigan, 2005).

The same information and communication technologies that enable these other activities offer opportunities in the health arena as well. For example, hardware is becoming smaller, more powerful, cheaper, and more portable. Software is evolving to permit the storage and integration of ever-greater volumes of information. Search engines are proliferating and becoming more robust. Communication technology is enabling greater speed,

the use of multimedia, and increasing mobility. All these factors can be conducive to wider dissemination of e-health tools, provided ubiquitous broadband access can be achieved.

There are many signs of the dynamism of the e-health environment, as demonstrated in the following examples.

- Manhattan Research reported in 2002 that the number of e-health consumers was growing at twice the rate of the overall online population (eHealth Institute, 2002, p. 16).

- The National Library of Medicine reported that the number of unique MedlinePlus users grew more than threefold, from 16 million to 52 million, between 2003 and 2004 (B. Humphreys, personal communication, December 6, 2004; *www.nlm.nih.gov/medlineplus/ usestatistics.html*).

- In the last week of March 2005, the Association of Cancer Online Resources (*ACOR.org*) delivered 1,524,367 individual e-mails around the globe (G. Frydman, personal communication, April 2, 2005).

- Recent surveys indicate that 80 percent of adult Internet users, or nearly half of Americans over age 18 (about 95 million), say they have researched at least one health topic at some point (Fox, 2005b).

- Two consumer-oriented applications— disease management and patient- centric portals—were included among nine "major HIT trends" (Healthcare Informatics, 2005).

- The major media regularly report e-health topics. For example, patient blogs and their proliferation are a subject capturing media attention; the *Wall Street Journal* called patient blogs "a new and more personal alternative to the plethora of disease-related Web chat rooms, message boards, and e-mail discussion groups" (reported in *iHealthBeat.org*, May 4, 2005).

- President Bush has made it a national policy goal that all Americans will have portable electronic health records, which they control, by the year 2014, and he created an office to coordinate progress on health information technology (Bush, 2004a).

- A RAND Corporation study found that 72 percent of adults sought out information for treatment decisions, and 69 percent of adults used the Internet more often than any other source for health information (RAND Corporation, 2005).

The growing diversity of the e-health market is itself an important sign of its dynamism. The momentum toward e-health now affects nearly every segment of society, albeit to a different extent. For example, the 5 to 7 million enrollees in the My Health*e*Vet program of the U.S. Department of Veteran Affairs (VA) can view parts of their health records and carry out health-related functions through personally controlled electronic health records (*www.myhealth.va.gov*). Significantly, so can the 1,500 migrant farmworkers enrolled in the California program MiVIA (profiled in the Preface). And every month, more than a third of

the 300,000 subsidized housing residents in the United States who use the Beehive (*www.thebeehive.org*), a Web site designed for persons with low literacy, visit its health section—consistently the most trafficked section of the site (S. Brachle, personal communication, March 2005).

Just a few years ago, the "typical e-health consumer" was described as "educated, middle- or upper-income, and an assertive and empowered buyer" (eHealth Institute, 2002, p. 16). Citing 1999 findings of Cyber Dialogue, Inc., Cain, Sarasohn-Kahn, and Wayne reported that "online health consumers behave in ways typical of *New Consumers* (individuals with a certain amount of discretionary income, experience with computers at work and/or at home, and the equivalent of at least 1 year of college education)" (2000, p. 14).

Although younger, better-off consumers continue to predominate in this market, the e-health consumer profile is slowly growing more multidimensional as new channels to e-health tools open and the number and type of stakeholders, intermediaries, and dissemination agents expand. Persistent disparities and the digital divide still require policy attention, but usage trends in the U.S. population are moving toward greater inclusiveness. Today's Internet users, for example, include more seniors, especially the cohort aging into that category (Kaiser Family Foundation, 2005); more Hispanics (*Hispanic Market Weekly*, 2006; Spooner, Rainie, Fox, et al., 2001); more African Americans (Spooner and Rainie, 2000); and more low-income Americans (Cain et al., 2000). In addition, evidence suggests that some traditionally underserved groups, such as seniors,

Hispanics, and African Americans, are even more likely than others to seek health information online (Gustafson, Hawkins, Pingree, et al., 2001; Zarcodoolas, Blanco, Boyer, et al., 2002).

Research also suggests that health status is a complex aspect of consumer interest in e-health. One survey classified online e-health users based on health status and found that "the well" comprised 60 percent of all e-health users, "the newly diagnosed" were only 5 percent, and "the chronically ill and their caregivers" were 35 percent (Cain et al., 2000). The researchers report that the "well . . . search for preventive medicine and wellness information in the same way they look for news, stock quotes, and products," whereas the "newly diagnosed . . . search frenetically and cover a lot of ground in the first few weeks following their diagnosis," but do not necessarily become consistent users. The authors call particular attention to the third group—the chronically ill and their caregivers, who "have the greatest potential to affect and be affected by Internet healthcare provision" because they have incorporated chronic illness management into their daily lives and "turn to the Internet for help" (quotations are from p. 1).

Using data from the Pew Internet & American Life Project, Houston and Allison analyzed health status for Internet users who go online for health information (2002). They found that those who rated their health either as fair or poor were newer users of the Internet but tended to use the Internet more frequently and were more likely to use information from online chats.

Consumers also vary in the stimuli causing them to seek out e-health resources. Some do so after learning about them from healthcare practitioners, media advertisements, or friends. Many health educators and healthcare practitioners, rather than producing their own educational materials, refer patients to Web-based resources or download and provide the information.

The concept of "information therapy," the prescribing of targeted information as part of a clinical encounter, has taken hold in healthcare organizations, such as Kaiser Permanente, and information providers, such as the National Library of Medicine. (See Center for Information Therapy [*www.informationtherapy.org*] for one perspective on the information therapy concept.) A significant percentage of e-health end users do not use the technology themselves, but rather come to the resources indirectly through relatives, friends, or other intermediaries ("infomediaries") who serve as caregivers or information sources. Manhattan Research estimated in 2003 that the "zone of influence" surrounding what was then 82 million e-health users extended to 135 million Americans (as reported in the eHealth Institute Summary Report, 2004, p. 13).

Another stream of e-health consumers comes to these tools initially not through personal initiative but in response to organizational programs. This source of momentum is significant in understanding the forces at work in the e-health market. The organizations in question engage their constituents in using e-health tools (developed, purchased, or leased by the organizations) as part of strategies to enhance services, reduce costs, or achieve other program objectives. The dissemination and marketing strategies used by such organizations may provide useful models for future efforts to widen access to and use of e-health tools.

## DIVERSE INTERESTS AND STAKEHOLDERS

The following sketches illustrate the variety of settings in which consumers encounter and use e-health tools, the factors influencing their e-health practices, and the range of e-health functions available. These characters are fictitious and in many ways idealized because many tools in the market do not have the multifunctionality, interoperability, reliability, and quality of the tools described below. The sketches are useful, however, to illustrate key points about e-health activities and the many purposes they could serve for funders, suppliers, intermediaries, and end users. The hypothetical value propositions involved are summarized in Table 4.

- *Ella* is the mother of Nathan, who has autism spectrum disorder. Ella uses a variety of e-health tools to get information about autism; keep a log of Nathan's treatments, behavior, diet, and other factors; and communicate with other parents of autistic children. She is also able to exchange periodic e-mails with the family pediatrician through her health plan's Web site.

- *Carlos* has just been diagnosed with prostate cancer. His doctor mentions several treatment options and, because it is a lot of information to process in

one visit, suggests that Carlos use an e-health tool to systematically consider and decide among his treatment options. The doctor also recommends a Web site that links Carlos to a national network of other men dealing with newly diagnosed prostate cancer.

- *Ed* has diabetes and lives in subsidized housing that was wired for Internet access when it was built. A neighbor who also has diabetes told Ed about the Beehive, a Web site designed for users in affordable housing. Through the Beehive, with his doctor's encouragement, Ed found more information about managing his disease and was able to connect to the American Diabetes Association site easily, where he found an e-health tool he uses to monitor his blood sugar at home. He reports regularly to his doctor, who monitors blood sugar levels and will contact him if a medical intervention is needed. Ed also keeps up with the latest medical research and tips on self-care through listserv bulletins from the Association.

- *Marian* is enrolled in a large health plan. Through its patient portal, which she can view either at home or at the outpatient clinic, she can see parts of her electronic medical record, refill prescriptions, make and change appointments, communicate securely with her physician, and link to health information Web sites recommended by her health plan.

- *Fran* needs to help her mother find a high-quality nursing home and is very concerned about both cost and quality issues. She downloads information from a Government Web site on nursing home costs and quality, and she enters it in a decision-support spreadsheet program that enables her to keep records of her mother's Medicare payments and medical expenses. Fran also uses a personal health record to keep track of her mother's medications, healthcare appointments, and daily blood pressure readings.

- *Hilary* works for a large company that, through its employee wellness program, is offering her financial incentives to lose 30 pounds and get her hypertension under control. The company offers employees free subscriptions to an online health management tool Hilary can use to find scientific information on nutrition and fitness and to keep track of her eating and exercise. Because she finds she needs extra support, especially at night when she tends to snack, Hilary also joins an online community that gives her peer contact around the clock.

- *Rosa* has decided to heed her children's urging that she get a mammogram. With their help, she views an online educational video and downloads illustrated Spanish-language information on mammograms and breast cancer from the kiosk at her community health clinic. Because her reading skills are limited, she appreciates the plain language, illustrations, and spoken narrative available on the kiosk. Her children appreciate the printed materials they can take away and refer to, to help Rosa understand and act on the advice.

- *Gregory* is a sixth-grader who has trouble with impulse control. At school,

his teacher builds into his curriculum a regular time to use a computer program to keep a confidential journal and play instructive computer games. The games help Gregory learn methods for controlling his impulses and getting along with his classmates.

- *Alan* is a college student who's been told he must cut down on his binge drinking if he wants to stay in school. His university provides an e-health tool he can use to record his goals, keep track of his drinking patterns, and maintain a confidential journal. He can enter his weight, number of drinks, and other variables into a calculator to determine what his blood alcohol content would be and the impairments that might result. For a reality check, he can also use the tool to compare his drinking to that of his peers.

As these sketches illustrate, individuals, groups, and organizations have a broad range of interests related to consumer e-health. Healthcare organizations and health plans are major drivers. A growing number of them, and especially large health plans, offer their enrollees portals that afford access to electronic health records, communication, and administrative functions within the institution as well as ancillary health management functions. For these organizations, patient portals can be both an attractive member benefit and a means of reducing administrative costs.

Some healthcare organizations and purchasers offer their enrollees disease management tools to improve care and possibly reduce costs. Disease management tools are an important facet of the Chronic Care Improvement Program of the Centers

for Medicare & Medicaid Services (CMS), which will be responsible for nearly half of all healthcare spending by 2014 (Heffler, Smith, Keehan, et al., 2005). CMS also is pilot-testing the Medicare Beneficiary Portal, an example of the kind of portal being offered to enrollees with information on health benefits, clinical content, and clinical transactions. If the CMS pilot is successful, the number and diversity of Americans with access to such portals will increase significantly.

The above sketches also illustrate that healthcare providers and purchasers are not the only public- and private-sector stakeholders in the e-health arena. For example, some large employers offer employees e-health tools as part of strategies to control healthcare costs and enhance employee health. Local, state, and national public health programs offer online prevention and behavior change programs and resources. Some schools encourage students to use e-health tools to help them deal with behavioral and health problems.

Table 4 summarizes the types of stakeholders in the e-health market and some of the interests motivating them. Nonconsumer stakeholders are particularly important for strategies to extend the reach and impact of e-health tools. Alliances and strategies formed around the vision articulated in the Preface should recognize the value propositions for every participant. It is possible that the relative benefits will vary for different stakeholders under different conditions. For example, the potential public health benefits may justify Government investment in e-health tool research, development, and dissemination for underserved populations

*Table 4.  Potential e-Health Value Propositions for Major Stakeholders*

| Stakeholder | Benefits Sought From Consumer e-Health |
|---|---|
| Consumers (e.g., patients, informal caregivers, information intermediaries) | • Private, 24/7 access to resources<br>• Expanded choice and autonomy<br>• New forms of social support<br>• Possibility of better health<br>• More efficient record management<br>• Lower cost healthcare services<br>• Avoidance of duplication of services |
| Consumer advocacy and voluntary health organizations (e.g., AARP, American Cancer Society) | • Greater capacity for health management and education for constituents<br>• New communication channels<br>• More efficient service to constituents |
| Employers, healthcare purchasers, and third-party payers | • Healthier employees more capable of health management<br>• Lower healthcare costs |
| Community-based organizations | • Constituents with greater capacity for health management and well-being<br>• Healthier communities<br>• Lower cost healthcare services |
| Clinicians | • Greater efficiency<br>• Better communication<br>• More adherent and satisfied patients |
| Healthcare organizations | • More patient self-care and health management<br>• Lower administrative costs<br>• Improved quality and patient outcomes |
| Public health programs | • A healthier population more capable of self-care and less at risk for avoidable disease |
| e-Health developers | • Sustained use of e-health products<br>• New sources of support for product development and evaluation |
| Industry and commerce | • New advertising vehicles<br>• Wider markets for products |
| Policymakers and funders (public and private) | • Effective means of implementing programs and policies<br>• Cost-containment or cost-reduction strategies<br>• Quality improvement strategies |

even if an uncertain return on investment makes commercial interests reluctant to take the risk.

## CHALLENGES FOR PUBLIC-PRIVATE PARTNERS

This report stresses that e-health tools have the potential to be part of the solution to health disparities and other policy challenges if appropriate e-health resources become available and useful to a larger proportion of the U.S. population than is now the case. Even though "technological innovation is a major driver of the global economy, quality of life, and [individual] health improvement," market forces so far have failed to harness these resources to improve population health (Eng, 2004).

Some observers caution that health disparities could worsen as a result of the uneven distribution of e-health tools or consumers' varying ability to use these resources. Unequal distribution and use of e-health tools could enable some Americans to improve their health and health care while others are left behind (IOM, 2002). Many e-health experts expect that health plans and providers will be the most influential drivers of the adoption of e-health technologies (eHealth Institute, 2005); if so, the large segment of the population without insurance or with no regular source of care will be further excluded from the modern healthcare system.

Public policy and market practices could undermine the benefits for population health in a number of ways. In the private sector, unconstrained commercial uses of health information technology, and in particular unauthorized commercial uses of personal health information, could engender mistrust among healthcare providers and patients. In addition, consumers' use of tools without an evidence base at best could be ineffective and at worst could waste scarce resources or cause harm. As for public policy implications, the severe economic pressures on policymakers discussed in Chapter 1 could generate aggressive, cost-driven policies that force consumers into technology uses and unsupported health decisions that are beyond their current capacities. For all the dynamism in the e-health marketplace and the congruity of public and private interests, it will take a commitment to the vision of this report and new levels of strategic partnership and leadership to produce population-wide health benefits from today's promising conditions. Some specific areas in which strategic efforts are needed are outlined in the following sections.

Even when partnerships offer the opportunity to fulfill value propositions for every participant, they are not likely to occur without leadership. This is especially the case when the ultimate value being sought is the public interest; in that case, the leadership almost certainly must come from the Government (Lansky, Kanaan, and Lemieux, 2005). The Office of the National Coordinator for Health Information Technology, U.S. Department of Health and Human Services (HHS), in collaboration with other HHS agencies and departments in the Federal Government, is tasked with providing leadership in health information technology. Consumer

empowerment is already part of the health information technology agenda and could accommodate the vision outlined in this report. Leadership can take many forms, including supporting research and demonstrations, convening stakeholders, participating in coalitions convened by others, setting examples through its own activities, and facilitating strategy development. Public policy should focus on developing and implementing strategies to reach those constituencies already on the margins of the digital mainstream, such as persons who are uninsured, have low income, or have disabilities, as well as on identifying incentives in publicly funded programs.

Exercising leadership in this way would augment and be synergistic with several leading Government programs. For example, in addition to the VA's new e-health tool, My Health_e_Vet, the U.S. Department of Defense has an electronic personal health management system for its constituents, Tri-Care Online. Several HHS agencies, including the National Institutes of Health, the National Library of Medicine, the Centers for Disease Control and Prevention, and the Office of Disease Prevention and Health Promotion, host multitopic, broad-based, consumer-oriented Web sites and provide digital informational materials for the public. The National Cancer Institute has a number of consumer-oriented e-health programs, some described in Chapter 5. Finally, as discussed above, CMS is beginning to offer digital technologies to help Medicare beneficiaries manage their benefits and self-care.

These activities are a good start, but most of these programs target specific constituencies (e.g., Medicare beneficiaries), functions (e.g., health information), or diseases (e.g., cancer). Given the value propositions outlined earlier, there are sound reasons to support connecting diverse governmental activities as part of a comprehensive, coordinated strategy akin to the current electronic health record initiative.

The current work on personal health records (PHRs) by industry and Government, separately and jointly, is likely to have an important impact on the future of consumer-oriented e-health. In addition, this activity provides a model for what can happen through targeted joint efforts. Connecting for Health, a collaborative of more than 100 public and private stakeholders from Government, the information technology industry, and health care, is working to "bring health care into the information age" through technologies such as electronic health records and PHRs (Connecting for Health, 2004).

PHRs are an emerging technology to enable people to manage their health information and healthcare transactions electronically. Although significant challenges need to be resolved with PHRs, some observers envision them as the gateway and possible platform for all consumers' personal health management activities (NCVHS, 2005a).

As noted above, the President increased the visibility and momentum for electronic health records when he set a national goal

that most Americans should have electronic health records by 2014.  The Office of the National Coordinator of Health Information Technology (HIT) bears major responsibility for advancing the President's goal, and PHRs are one of the goals in the Strategic HIT Framework promulgated in 2004.  Former National Coordinator Dr. David Brailer describes the purpose of the office as helping to create the conditions in which the market can deliver health solutions to the nation (Lansky et al., 2005).  These activities model the kind of strategic partnerships that will likely be necessary to address the challenges outlined below.

## Challenge 1:  Linking Development, Evaluation, and Dissemination[1]

The preceding chapters discuss this study's findings about the significant gaps in e-health tool development, evaluation, and dissemination.  Chapter 2 outlines the challenges in developing tools for diverse populations.  Chapter 3 describes the emerging evidence of the benefits of e-health tools and the fact that the research does not translate into broad use of evidence-based tools outside the laboratory. As Chapter 1 discusses, this study found that the tools in widest use have not been evaluated by unaffiliated third parties, while those that have been the subject of rigorous research often are not widely available.  In other words, alignment is lacking between the e-health tools with the best evidence and

[1] This section is based on discussions with developers, researchers, and public health professionals in interviews, a special conference call on dissemination issues, and a November 2004 review meeting.  See Appendix 2 for a list of participants.

the ones that most consumers encounter. For example, although the popularity of commercial dieting Web sites may be a sign of the dynamism of the e-health market, questions remain about the scientific basis of the content as well as the short- and long-term behavioral and health effects of the tools.

Researchers and funders report that it is difficult to get evidence-based e-health tools into broad and sustained public use.  A major reason for this problem, according to study informants, is the lack of coordinated and balanced funding for development, evaluation, and dissemination, with the bulk of funding supporting only the first two steps.  Tools that are developed with Federal and foundation support are generally tested with small, targeted populations.

Funding is not available for sustained dissemination, much less for reaching a significant proportion of the population or for long-term evaluation.  Connie Dresser, who coordinates the National Cancer Institute's Small Business Innovation Research program (described in Chapter 5), points out that this leaves unanswered the question of "real-world" effectiveness (C. Dresser, personal communication, September 10, 2003).  In addition, an opportunity is missed to obtain empirical information on the factors that support or undermine sustained consumer use. The failure to get tools into circulation particularly affects population groups with the most to gain from a greater investment in dissemination, which is an important policy consideration given that many of the tools designed for underserved

communities are created with foundation or governmental support.

Developers and researchers are a good source of ideas about possible solutions. Study informants point to the need for restructured funding and broader notions of research "success"—in both instances, to include dissemination. They note that as noncommercial developers, most researchers lack the capital and skills to get their tools out to the public. Their isolation from the world of implementers is a major barrier to more effective dissemination of evidence-based tools. Creating a collaboration between these groups, informants say, would require cultural and structural changes within the research field, such as translating technical and scientific jargon into marketing language and reframing rewards so that all stakeholders get a return on their investment.

In addition, developers express interest in learning from the successes of commercial products and applying that learning to getting beneficial tools into broader use. Some cite the pharmaceutical industry, with its sophisticated mechanisms for moving products from inception to market, as a model for a similar "chute" for communication and e-health tools. Fundamentally, the researchers consulted for this project assert that Government and foundation funders should accept more responsibility for the diffusion of products that are developed with their support, provided they are shown to be efficacious. This way, high-quality tools might actually reach the users for whom they were designed.

## Challenge 2: Building Economic Viability and Sustainability

Better links among tool development, evaluation, and dissemination could help balance the related goals of expanding markets and raising the standards for e-health tools. This linkage could go a long way toward addressing the sustainability issues that are a common concern of many e-health developers. Sustainable business models are an essential building block in the broad vision for consumer e-health. Government may have to spearhead strategies to reach underserved populations that could benefit from e-health tools but may not initially or ever be able to pay for them. Nevertheless, Government alone cannot underwrite tool development and dissemination on a large scale, so there can be no widespread dissemination and adoption of evidence-based tools without successful commercialization. This was a recurrent theme in conversations during this study, as it is among developers themselves.

e-Health developers are based in public health and public interest organizations, health care, academia, and business as well as in the communication arms of several Government agencies. Their funding sources include grants, investments, and large organizational budgets. As noted, Government and foundation research grants are a major source of financing for tool development and evaluation. After the research and development stage, private-sector developers need realistic business plans to continue production, upgrading, and dissemination. The business models for consumer e-health tools include

advertising, sponsorship, licensing, fee-for-service, subscription, and the services of "bricks and mortar" healthcare delivery systems (Eng, 2001, pp. 34-37).

A cross-section of e-health leaders from public health, computer science and technology, health care, academia, and business has been addressing common interests and concerns in eHealth Developers' Summits since 1999 (eHealth Institute, 2002, 2003, 2004, 2005). The summaries of these meetings provide a window on developers' perspectives; issues they, their business partners, and their clients face; and other themes in the e-health environment. In general, a growth in optimism about the viability of e-health can be traced from the time of the 2000 dot-com crash through the ensuing Summit summaries. Nevertheless, the search for sustainability business plans for e-health developers stands out as a persistent concern. As the summary of the 2001 meeting stated, "Strong proof of ROI [return on investment] remains elusive for most eHealth solutions, and realizing tangible financial benefits from eHealth is probably a long-term process" (eHealth Institute, 2002, Executive Summary; see also eHealth Institute, 2005, pp. 30-36).

A fundamental part of the problem is that although consumers are the intended end users of these products, few are in a position to pay for them for a wide variety of reasons. For both large and small developers, there is thus a mismatch between users and purchasers. Even consumers who recognize the health benefits of e-health tools and want to use them generally expect another entity to pay for them (Connecting for Health, 2004). Simply

put, the market has not yet identified a uniformly successful price or sales model for consumer information Web sites and other e-health tools.

The information derived from interviews for this study on 40 e-health tools, although not necessarily representative, illustrates the sometimes roundabout route to consumers and the disconnect between payers and end users (see Appendix 1). The interviewees report that consumers—who are by definition the end users of all the e-health tools—pay to use only 9 of the 40, and only 3 tools are exclusively distributed directly to consumers. In some cases, developers produce commercial direct-to-consumer versions as well as others that are made available through business partners. Tools in the latter group usually have more functions, customized to the business partner's specifications. Partners in the categories listed in Table 4 disseminate 37 of the 40 tools in this group. Thus, consumers gain access to them in their capacity as employees, health plan members, national health organization constituents, and so on. Relatively few developers have the funding to conduct rigorous scientific evaluation of their tools; most conduct cost-benefit studies comparing health service utilization, absenteeism, or other variables related to the cost of distributing the tool, to demonstrate their products' ROI for purchasers.

On the subject of the research-dissemination disconnect, eHealth Summit discussions identify integrating research findings into viable real-world products as a particular challenge for developers. The 2004 Summit group voted "lack of expertise to translate research findings into practical product modifications" as the chief reason

why there is not more e-health research. This followed the 2003 meeting's call for alliances and partnerships between academic researchers and commercial companies with common target audiences, to speed dissemination and diffusion of findings into marketable products.

A public interest perspective requires that profitability be combined with quality, utility, privacy, continuity, and other values for consumers. Finding commercial models that allow developers and suppliers to satisfy business requirements while also serving the public interest is an important challenge facing policymakers and others who hope to stabilize the market and expand the public benefits of e-health tools. Arguably, the dual goals of market stability and wider reach for e-health tools are synergistic. Opening new markets could increase the financial viability of e-health developers. Seventy percent of the 2003 eHealth Summit participants favored this idea, indicating in a survey that they saw market potential in underserved communities (eHealth Institute, 2004).

Healthcare reimbursement and payment policy is another important part of the solution. The former National HIT Coordinator Dr. David Brailer captured a key attribute of e-health: "Today's reimbursement policies are based on the premise that legitimate care is only done in proximity to a doctor, and that needs to change. Care does not have to be the same place and time as the doctor; it includes daily monitoring, e-mail, and more. Modern policies need to incorporate the consumer in self-management" (cited in Lansky et al., 2005).

## Challenge 3: Protecting Privacy and Nurturing Public Trust

Protecting the privacy of personal health information in e-health tools is another "public good" requiring attention from policymakers and private-sector partners. This issue is highlighted here for two reasons: first, the well-documented privacy concerns of consumers, healthcare providers, and others could impede the adoption and use of e-health tools and limit their benefits (California HealthCare Foundation, 2005); and second, the well-being of users is at risk if privacy protections are inadequate.

Surveys show that consumers rate personal health information as one of the two most sensitive types of consumer personal information (along with financial information), and they are concerned about the electronic collection and use of their medical records. Individuals with serious and/or genetically based health conditions express the greatest concern (NCVHS, 2005b). Many consumers fear identity theft as well as discrimination against them in employment, insurance, or other areas based on their health status. Some people fear that their privacy is at risk when they are surfing the Web, and many who use health information Web sites do not share their personal data (Westin, 2005).

People's fears about abuses, especially related to electronic medical records, are not unfounded, as confirmed in the daily newspaper. Policymakers, healthcare organizations, developers, and public-private collaborations take these issues seriously and are working on laws,

regulations, and security mechanisms to prevent or at least minimize privacy abuses. Consumers' attitudes toward privacy and electronic personal health information vary widely.  Although some people express fear about any electronic processing of health records, others celebrate the benefits of this technology and freely share private information in public online communities. The developer interviews for this project provide anecdotal information about some consumers' practices in this area as well as developers' approaches to protecting privacy.  Information from the interviews together with observation of Web sites reinforce the point that consumers exhibit widely ranging attitudes toward health privacy (see Appendix 1).

This area warrants further research into consumer attitudes and practices as work continues to improve laws, regulations, and security mechanisms.  The heart of the question before policymakers is how to nurture an atmosphere of justified public trust.  Doing so requires establishing adequate security mechanisms and respecting consumers' choices about sharing information in different circumstances. It also involves cultivating in consumers an appreciation for the potential benefits of health information technology—for themselves and their families.  As awareness grows about the seriousness of these issues, a number of public and private groups are working on health information privacy and security.  They include the National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality, which advises HHS, the HHS Privacy Advocate, the HHS Office of Civil Rights (which enforces the Health Insurance Portability and Accountability

Act [HIPAA]), and several university-affiliated institutes.

## Challenge 4.  Assuring Quality

The quality of information and tools available on the Internet is an ongoing and unresolved issue in the e-health field.  Apart from privacy and confidentiality issues, public trust can be undermined by doubts about the reliability of the information and claims from either commercial or governmental sources.  Although health Web sites can be reviewed and accredited by established organizations, such as URAC (American Accreditation HealthCare Commission, Inc.), accreditation remains an underused practice in this sector.  The cost of accreditation and an apparent lack of consumer demand for it have resulted in a limited number of sites seeking accreditation (see the list of accredited Web sites at *www.urac.org*).

The research review in Chapter 3 as well as the interview reports in Appendix 1 indicate that researchers are trying to determine consumer behavior toward quality assessment and identify mechanisms to enhance and signal quality to consumers. Quality assessments of e-health tools, however, are an elusive target and depend in large part on editorial processes, judgments about what constitutes reliable and credible sources of information, and an ever-changing body of scientific knowledge about health conditions and their causes, effects, and treatments. Beyond the *Healthy People 2010* objective on the proportion of health Web sites that disclose information to assess the quality of the site and past interest from the Federal

Trade Commission in fraudulent health claims and privacy policies, there has been little public policy attention to matters of information quality on the Internet.

If e-health tools evolve primarily as a part of health plan and provider operations, then quality assurance of the tools may become a routine part of business. Consumer behavior suggests, however, that finding and comparing Internet health resources is a popular activity and one unlikely to be eliminated by the greater availability of provider portals. Consumers may not be clamoring for public action on quality assurance, but quality may nevertheless become a public policy matter if consumers end up choosing questionable tools that result in higher costs and worse health outcomes.

## SUMMARY

This chapter portrays a dynamic e-health arena and identifies the gaps that must be filled to transform it into one from which more Americans can benefit. The goal, as outlined in Chapter 1, is to get appropriate evidence-based tools into wide and sustained use to improve population health. The steps that must be taken to achieve this goal, as outlined in this chapter, include linking e-health tool development, evaluation, and dissemination; building viability and sustainability; protecting privacy; and assuring quality.

This chapter profiles the many interests at play in this environment. The stakeholders who share an interest in consumer e-health include consumers themselves, developers, and researchers as well as healthcare organizations, purchasers, employers, public health programs, and governmental institutions. All are potential participants, in various combinations, in efforts to create the conditions in which many more Americans can enjoy the benefits of appropriate e-health tools. Moving beyond the status quo requires collaboration among stakeholders who see and take action beyond their customary boundaries. This chapter mentions several such collaborations, and Chapter 5 profiles others. A large gap that remains to be filled is leadership and coordination within and between the public and private sectors.