

PREFACE: A VISION OF E-HEALTH BENEFITS FOR ALL

This report summarizes a study undertaken by the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, on the potential utility and value of consumer e-health tools for populations that experience health disparities. As the report notes, the rapidly expanding use of information and communication technologies, particularly the Internet, by multiple sectors of the population indicates that there is an opportunity to use these same technologies to improve population health. Many conditions, however, must be met before opportunity becomes reality. The report examines and describes the most significant requirements as well as provides a vision to help guide the development of an inclusive environment of e-health benefits for all.

The following fictional profiles of Juan Lopez and Barbara Jones personify two emerging groups of e-health consumers. Barbara is a well-educated, middle-class female, age 47, who is actively involved in managing her health and that of her family and knows a lot about health and health resources. She owns multiple computers (desktop and mobile), has high-speed Internet connections, and is technologically savvy. Juan, age 34, is an equally important part of the e-health vision articulated in this report and of the reality described here, even though he has none of these characteristics, has limited health literacy, and is new to e-health.

Juan and Barbara have more in common than might be apparent at first glance. Both have access to e-health tools that provide new and vital information about their health. Both are concerned enough about their health and that of their families to want to be involved in managing it and making informed decisions. For different reasons, both know they need to rely on themselves, not just healthcare professionals, for continuous and complete care, and both are learning to use several interrelated e-health tools for these purposes.

Juan, Barbara, and their families are introduced here to illustrate the breadth and diversity of the e-health landscape depicted in this report. In addition to the user-centered approach proposed for all e-health tools, Juan's story illustrates the need for outreach, community technology access, and training to create the conditions for meaningful access for all population segments. With these additional investments, e-health resources can serve his needs and interests as well as they do Barbara's and can promote equity in healthcare services and information access.

Juan Lopez and his family are migrant farmworkers who follow the crop cycles through the western United States, arriving by late summer in Sonoma Valley, California, for the grape crush. There they live in simple housing and receive health care from the St. Joseph's Healthcare Services Mobile Medical Units and other services from Vineyard Worker Services (VWS). Since 2002, Juan and his wife, Maria, have been able to maintain electronic health records for themselves and their children through the MiVIA program (www.mivia.org). Their password-protected personal health records contain their providers' records on medical visits, test results, and other clinical data. In addition, they can keep records on their son Lupe's blood sugar and other health matters and communicate with the doctor through secure e-mail.

At the first visit to the VWS clinic, the outreach worker, Ricardo, helped enroll the Lopez children in the Healthy Families public insurance program. Now that they have access to primary care, the family is able to avoid the emergency department visits that used to punctuate their lives. When Lupe was diagnosed with juvenile diabetes, Ricardo downloaded self-care information in Spanish from MedlinePlus, showing Maria how to search for information through her MiVIA Internet connection. He also printed Spanish-language information on the family's prescriptions, making them much more comfortable in taking the confusing medications. Juan likes the fact that he can keep notes on the shoulder pain he's experienced for years so he can describe it to his doctor.

One of the most valuable MiVIA resources for the family is the portable personal emergency card, providing electronic access to information on health conditions, medications, allergies, immunizations, and enrollment. Wherever they go, these cards enable family members to share information with medical providers and to maintain a continuity of care record. Juan's shoulder problems are less acute, Lupe now receives consistent care for his diabetes, and the children did not require re-immunization because their schools and doctors have their immunization records. Juan and Maria can access their personal health record home pages and link to the Internet on public computers set up by the California Endowment in several locations in the valley.

When they first heard about VWS, Maria and Juan were both leery about trusting a public clinic and even more so about keeping their records electronically on MiVIA. However, the trained *promotora* (community health worker) they met at the laundromat assured them that the program exists only to help them and that their privacy would be protected. Within a few months, Maria was so enthusiastic about the program and her new sense of empowerment that she agreed to join the VWS Farmworker Advisory Group.

Barbara Jones runs her own business, a travel agency, and uses technology for her home business and to manage her own health as well as that of her family. They own two desktop computers and multiple mobile computing devices, all with high-speed Internet connections. Her husband Doug has asthma, and their son Jonathan has a learning disability.

As do most consumers, Barbara uses a search engine to find information on the Internet. After spending a lot of hours surfing and sorting through Web sites—some with reliable information, others pitching quick fixes and unproven products—Barbara found www.healthfinder.gov, the Federal Government’s gateway Web site for consumer health information. Barbara returns regularly to the site, most recently to browse the section on perimenopause and take a quick quiz. She downloaded the information into her personal library in her online personal health record. She also read the privacy policy of www.healthfinder.gov and was reassured that the site does not collect or store information about its users.

Barbara has a membership with a commercial Web site where she has created personal health records for herself and her family. Before she selected this site, she spent many hours analyzing different services and companies. Barbara settled on a site that clearly explained its services, pricing, and guarantees, including privacy protections. She uses an ID and password to access the records.

On a typical day, Barbara receives system reminders in her e-mail to log in and record any updates on her husband’s and son’s conditions. Barbara plans to review Jonathan’s new medications that the doctor prescribed yesterday and the calendar with the automated reminder system for Jonathan’s next visit. She also will double-check the time of an appointment she has scheduled with a cardiologist. Barbara completed an online assessment that suggested she might be at risk for heart disease and should consult a physician.

Barbara’s women friends use many of the same online health resources she does. Several have tried a popular online weight loss program, and one has used an online program to quit smoking. They all like the convenience and privacy. She and her friends often share tips that they glean from various chat rooms. In her town, few of the office practices have electronic health records, let alone personal health records and other tools for their patients. Barbara did receive a mailing from her health plan telling her that they would add new features to their Web site; however, at present, the site contains only general benefits information, provider directories, and health information that she already finds on her own. She is comfortable being ahead of the curve and feels she is getting better care for her family by using online information and services.

A VISION FOR CONSUMER E-HEALTH FOR A DIVERSE POPULATION

The illustrations above suggest that a broad and inclusive vision of consumer e-health is needed to ensure equitable access and appropriate content for all. This report proposes the following vision to help shape emerging policies, research, and practices. The vision is only the first step needed to galvanize attention, motivate action, and stimulate partnerships to create a sustainable consumer e-health arena.

- Consumers with diverse perspectives, circumstances, capacities, and experiences are included in the design of, and have meaningful access to, evidence-based e-health tools with strong privacy and security protections.
- Diverse consumers have the skills and support to evaluate, choose, and use e-health tools to derive benefits for themselves and those they care for.
- Healthcare organizations and practitioners use the full range of e-health tools to engage and support diverse consumers in their own health management as a routine element of care.
- Local, state, and national policies and programs support the sustainable development and dissemination of evidence-based consumer e-health tools to diverse individuals and communities, including those served by safety-net providers.
- Alliances and partnerships facilitate sustained consumer access to and use of e-health tools, consistent with the value propositions and perspectives of each participating stakeholder.
- Appropriate funding and incentives exist in public policy and the market to enable sustainable business models for tools with demonstrated effectiveness.



A CAVEAT ABOUT PRIVACY AND USABILITY

Since the beginning of this study, the interrelated issues of trust, privacy, and consumer control have moved to center stage in public policy discussions. These issues are clearly of critical importance to consumers, as shown in survey and focus group research by the Connecting for Health consortium and others. The security measures being developed, combined with education and transparency about the uses of personal information, are essential to assuring consumers that everything possible is being done to protect their personal information.

The vision stated above specifically includes the requirement of strong privacy and security protections, but the report does not include in-depth discussions of privacy, confidentiality, and security issues that are currently being addressed in other venues (for example, see the public record of the Subcommittee on Privacy and Confidentiality, National Committee on Vital and Health Statistics at www.ncvhs.hhs.gov). What the present study does contribute is the recognition that population diversity plays a role in understanding consumer attitudes and needs in this area, as in others. Individuals, as well as population groups, view the tradeoffs between the benefits and risks of electronic health information differently, suggesting the need for some choice in functionality and types of e-tools, as well as targeted education, communication, and support. Chapter 2 discusses this idea as part of the constellation of factors that require further consumer research and analysis.

At the same time that privacy and consumer control should be taken seriously as factors inhibiting the spread of consumer e-health tools, equal attention should be given to factors of usability. It is possible to envision a scenario in which consumers are satisfied with the control they have over their personal information, yet are frustrated by e-health tools that do not meet their usability requirements. For example, envision a personal health record that has the most advanced security features and sound privacy policies and guarantees consumers control over access to the record. This same personal health record, however, may also be designed in such a way that it is difficult to enter or transfer information from one application to another, involves too many steps to set up the record or conduct a transaction, displays confusing or overwhelming amounts of information on each screen, and is lacking in adequate technical support.

Consumers should not have to choose security, control, *or* usability. As the vignettes illustrate, consumers seek security, control, *and* usability. The key message of this report is that, without a greater focus on user requirements and accessibility issues, consumer e-health tools may fall far short of their potential for personal health management or population health improvement.