Federal Health Web Sites: Current & Future Roles

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Summary—An examination of the current and possible future roles of federal health Web sites, this paper provides an overview of site categories, functions, target audiences, marketing approaches, knowledge management, and evaluation strategies. It concludes with a look at future opportunities and challenges for the federal government in providing health information online.

The Internet has become part of Americans’ lives. As a tool to find information, transact business, and connect with others, it has become a routine part of the day for millions of people. According to a recent government report, over half the population, or 143 million Americans, was using the Internet in September 2001—a number that has grown at the rate of 20% a year since 1998. Increasingly, the public is turning to the Internet to assist in health care decision-making. While e-mail was the top reported online activity (84% of the population), searching for information about health services and practices (34.9%) and government services (30.9%) were among the most frequently cited online activities in the government report.

The magnitude of the Internet as a resource in consumer health care decision-making has been studied in several surveys. Harris Interactive recently found that 110 million adults sometimes go online to look for health information—a number that has almost doubled since 1998. Another survey, conducted by the Pew Internet and American Life Project, found that 73 million American adults (62% of those with Internet access) have used the Web to get health or medical information. Importantly, 61% of respondents said the Internet has improved the way they take care of themselves either “a lot” or “some.” Interest in health information crosses the age spectrum, with 42.7% of those over age 55 using health information online and three-fourths of American Internet users between the ages of 15 and 24 using the Internet to find health or medical information.

In addition to searching for online health information, Americans are also using the Internet to visit federal, state, and local government Web sites. A January 2002 survey indicated that 58% of American Internet users, or 68 million adults, had visited at least one government Web site—a sharp increase from the 40 million who had used sites in March 2000 when first polled. The report found that 49% of those using government Web sites sought advice or information about a health or safety issue, while 63% found out about government services and 20% got information about, or applied for, government benefits.
This paper examines the current and possible future role(s) of federal health Web sites in providing medical and health information to the public. It is based on the author’s review of many current federal health Web sites, supplemented by interviews with fourteen federal officials involved in their development and maintenance. While most of the Web sites reviewed were those within the federal Department of Health and Human Services (DHHS)—it is important to note that other federal agencies provide health information to the public or a particular constituency. These include, for example, the Federal Trade Commission’s information on consumer health fraud, the Department of Agriculture’s materials on nutrition, and the Veteran’s Administration’s, Department of Defense’s, and Office of Personnel Management’s information on health benefits.

OVERVIEW

Categories

There are several categories of federal health Web sites available to consumers. The first type is a cross-government agency portal site that includes health information as one topic among a broad range of available information for the public. The most prominent of these is FirstGov.gov. The site first opened in September 2000 and was relaunched in February 2002. Within the “Citizen Gateway” portion of the site, links to interactive online health information are available (http://first.gov/Citizen/Services.shtml), as well as a list of health topics on general and specific health and nutrition topics, health insurance, state and local resources, and consumer safety (http://first.gov/Citizen/Topics/Health.shtml). In addition, there are other cross-agency and cross-topic sites for particular audiences that include health information as one of their topics. These include FirstGov for Seniors (http://www.seniors.gov), maintained by the Social Security Administration; FirstGov for Consumers (http://www.consumer.gov/health.htm), which includes consumer protection information from several federal agencies; and FirstGov for Kids (http://www.kids.gov).

Other cross-agency portal sites focus exclusively on health. Healthfinder.gov (http://www.healthfinder.gov) provides links to hundreds of federal and nonfederal Web sites organized by condition or disease topic, audience (women, children, etc.), and health providers and insurance. The project is coordinated by the DHHS Office of Disease Prevention and Health Promotion with the active participation of a steering committee composed of federal agency representatives and nonfederal consumer health information specialists, librarians, and others actively engaged in online consumer health information.
Another health portal—MEDLINEplus (http://www.medlineplus.gov)—is maintained by the National Library of Medicine (NLM). The site has information on over 500 diseases and conditions from the National Institutes of Health and other government and nongovernment sources. There are also lists of health professionals and institutions, a medical encyclopedia and dictionary, health information in Spanish, prescription drug information, and links to thousands of clinical trials.

A final type of health portal is one that targets a particular health-oriented audience and brings together cross agency and nonfederal resources and links. The focus of these sites may be very broad, for example, women’s health (http://www.4women.gov), girls (http://www.girlpower.gov), or minority health (http://www.healthgap.omhrc.gov). Or, the focus may be very specific, for example, potential organ donors (http://www.organdonor.gov), patients or families looking for a clinical trial (http://www.clinicaltrials.gov), or those wanting information on fitness (http://www.fitness.gov).

A second category of federal health Web sites is maintained by DHHS and the agencies within it. The DHHS site (http://www.dhhs.gov) provides access to all agencies within the department. It is currently being redesigned to better meet the information needs of the public. Every federal agency within the department maintains its own Web site, with many of the agencies also having sub–Web sites that parallel their organizational structure. For example, the homepage for the Health Resources and Services Administration (HRSA) includes links to each of its program areas, such as HIV/AIDS, primary health care, maternal and child health, health professions, and rural health. In some cases, the sub-unit Web sites may all have the same “look and feel.” In other cases, they may each have their own design and navigation approach.

FUNCTIONS

Federal health Web sites serve consumers in a variety of ways. They help consumers learn about a health topic, find a resource they need, choose amongst various health care options, change a health behavior, and participate in the policy process. Each of these functions is further discussed below.

Learning about Health Topics and Programs

All federal health Web sites help consumers learn about a health issue by providing online information and educational materials. Many health sites include an A–Z disease or condition topic list on or near their home page. For example, clicking
on the topic “diabetes” at the MEDLINEplus site (http://www.nlm.nih.gov/medlineplus/diabetes.html) brings up a page that includes the following categories of information about diabetes: the latest news, a general overview of the disease, relevant clinical trials, alternative therapies, coping strategies, symptoms and diagnosis, disease management, nutrition, prevention/screening, research, specific aspects/conditions, treatment, glossaries and dictionaries, policy issues, and relevant organizations. There is also information on diabetes specifically for children, men, women, teenagers, seniors, and Spanish-speaking users.

In addition to information about diseases and conditions, federal health Web sites also provide information about how to be a better health care consumer. For example, the Agency for Healthcare Research and Quality (AHRQ) publishes a booklet on patient safety called Twenty Tips to Prevent Medical Errors (http://www.ahrq.gov/consumer/20tips.htm), and the Food and Drug Administration (FDA) publishes tips and warnings about buying medicines online (http://www.fda.gov/oc/buyonline/default.htm). Finally, federal Web sites provide information about federal health programs, such as Medicare (http://www.medicare.gov), the Indian Health Service (http://www.ihs.gov), or the State Children’s Health Insurance Program (http://www.insurekidsnow.gov), for which the public may qualify.

Finding Health Information and Resources

Most federal health Web sites include both consumer-oriented educational information generated by the sponsoring agency and links to information provided by other federal agencies, private nonprofit organizations, and, in some cases, commercial organizations. These types of organizations include voluntary health organizations (such as the American Diabetes Association), physician organizations, university and research groups, and commercial entities such as news services and online journals. In some cases, federal health Web sites include selection policies regarding links from their sites to other organizations. The policies include criteria such as the quality, authority, and accuracy of the linked site’s content, availability and maintenance of the site, and the breadth of information provided.

Referral to state and local resources that can help with a health problem is another function maintained by some federal health Web sites. For example, HRSA provides a database of community health centers and other primary care resources accessible by city, state, or zipcode (http://www.bphc.hrsa.gov/databases/fqhc). The Centers for Medicare and
Medicaid Services (CMS) provides an online directory of contact information and phone numbers for a wide range of state agencies offering services to Medicare beneficiaries (http://www.Medicare.gov). The Substance Abuse and Mental Health Services Administration maintains databases of substance abuse and mental health programs nationwide (http://www.samhsa.gov/public/look_frame.html).

Choosing among Health Care Options

Federal health Web sites also provide information to support consumers in a variety of health care decisions. In addition to educational information to help with decisions about treatment, mentioned above, federal health information also supports decisions about choosing and using health care. AHRQ provides a variety of materials that help patients choose quality health care services. These include checklists or questions consumers can ask about health plans, doctors, hospitals, and long-term care facilities. They also provide a set of questions consumers can ask when considering surgery (http://www.ahcpr.gov/consumer/surgery.htm).

Decision support through the provision of comparative organizational information is another function performed by some federal health Web sites. Medicare.gov provides searchable databases that identify and compare nursing homes, Medicare HMOs, Medigap plans, and end-stage renal disease dialysis facilities on a range of measurements, including organizational description, benefits, quality, and customer satisfaction. Medicare.gov is moving towards more customized decision support through its Medicare Personal Plan Finder (http://www.medicare.gov/MPPF/home.asp). After answering a few demographic and interest questions, the user is presented with a narrower choice of plan options to investigate further.

Changing Health Behavior

Encouraging health care behavior change is also a function of some federal health Web sites—although this type of functionality was less often mentioned by those interviewed and was less common on federal health Web sites. Stopping harmful health habits, such as smoking or substance abuse, or encouraging positive health habits, such as exercise or good nutrition, is the focus of some federal efforts. Healthfinder.gov includes a section of online interactive resources (checklists, questions and answers, etc.) that provide links to sites that assist consumers in identifying depression, planning menus, or checking for physical activity levels. The Centers for Disease Control
and Prevention (CDC) maintains a number of Web sites to support public health campaigns, such as bone health for young women (http://www.cdc.gov/powerfulbones), safe food handling (http://www.fightbac.org/main.cfm), and colorectal cancer screening (http://www.cdc.gov/cancer/screenforlife/index.htm).

In some cases, behavior change is encouraged by online documents such as the Public Health Service’s consumer guide, “You Can Quit Smoking” (http://www.surgeongeneral.gov/tobacco/consquits.htm), or referral to a range of “How to Quit” resources maintained by the CDC (http://www.cdc.gov/tobacco/how2quit.htm). Fitness.gov—the Web site of the President’s Council on Physical Fitness and Sports—includes a number of resources to help people of all ages exercise regularly.

Participating in the Policy Process

A few federal agencies explicitly use their Web sites to encourage citizen participation. For example, the FDA’s home page includes a “Let Us Hear From You” heading that has links to pages encouraging consumers to report problems associated with products regulated by the FDA, as well as a link to explain how to comment on proposed regulations. Another agency—the Federal Trade Commission—encourages the public to submit consumer complaints, including allegations of health fraud, through an online form (https://rn.ftc.gov/dod/wsolcq$.startup?Z_ORG_CODE=PU01). The information is entered into Consumer Sentinel, a secure database accessible to law enforcement agencies worldwide.

TARGET AUDIENCES

Federal health Web sites provide information to a variety of audiences. Some are exclusively designed for consumers, while others include consumers as one of numerous audiences, including health professionals, researchers, the health industry, or health policymakers. Consumers are targeted either directly by federal health Web sites or through intermediaries that deal directly with consumers.

Most federal agency health Web sites have a heading on their home pages that indicates consumer information or materials. AHRQ’s Web site differentiates between “consumers” and “patients” in its display, while the FDA uses the word “patients” as its home page entry-point. Many Web sites further segment their audiences by bundling information that is gender-specific (men’s health, women’s health), stage-of-life-specific (infants, kids, teens, seniors), role-specific (parents, caregivers), culturally or ethnically specific (minority, African-American,
Asian–Pacific Islander), benefits-specific (Medicare beneficiaries, Indian Health Service enrollees) or language-specific (Spanish, Asian languages). Other approaches to audience segmentation include information for those with a particular condition (e.g., cancer), those who are disabled, or those who travel to other countries. 

In addition to targeting consumers directly, many Web sites explicitly try to reach intermediaries that ultimately interact with consumers and patients. These include health professionals of all kinds, the media, employers, educators, libraries, and state and local programs. Many agencies also supply commercial health Web sites with federal health information they may use on their sites. Some agencies also link their Web site information to 1-800 call centers that might answer more specific consumer questions and provide hard copies of publications. For example, Medicare’s site (http://www.medicare.gov) is linked to the CMS call center 1-800-MEDICARE, while the National Cancer Institute’s Web site (http://www.cancer.gov) provides LiveHelp, a program staffed by information specialists who can answer questions received either by e-mail or by calls to 1-800-4-CANCER.

MARKETING AND PROMOTION

Federal health Web sites use a variety of mechanisms to make their audiences aware of their information and services. Almost all of those interviewed mentioned their agencies’ use of print materials (e.g., newsletters and reports) and other public resources to promote their URLs. The issuance of media press releases and other press advisories to highlight agency Web sites is widespread, with a particular focus on media that directly reach consumers, such as Parade magazine and newspapers. In some cases, federal agencies purchase paid advertising in consumer magazines; the National Women’s Health Information Center (http://www.4women.gov), for instance, has advertised in the Ladies Home Journal. CMS included the Medicare Web site in paid advertising in a wide range of consumer magazines during the fall of 2001 and saw its usage increase dramatically.

Federal health Web sites are also promoted through systematic contact with organizations such as voluntary health organizations (e.g., the American Cancer Society) that reach consumers. Participation in conferences as presenters or exhibitors was also mentioned by several federal health Web site officials as an effective promotional tool, as was working with regional DHHS office staff who work with local and state agencies in their areas.
Several health Web sites maintain electronic mailing list services (listservs) that periodically e-mail information about changes, updates, and other news about their sites to interested individuals and organizations. Several have also tried direct mail outreach to intermediaries who would be interested in their sites. For example, AHRQ has sent information to targeted opinion leaders, associations, and business groups that included information on their site. The Office on Women’s Health sent a mailing that included a magnet imprinted with the URL of the National Women’s Health Information Center Web site to over 80,000 nurse practitioners.

Finally, several Web site staff mentioned efforts to work with search engines to maximize their rankings in search engine results. Becoming familiar with and then using the search engine’s keywords in manual submissions is one strategy used. Some agencies are also exploring the use of special software or other services to optimize submission to top search engines.

**EVALUATION**

All of the federal health Web sites reviewed and contacted maintain periodic reports about usage on their sites, including metrics such as the number of hits, page views, visitor sessions, most and least requested pages, and most downloaded files. They also get information on how visitors get to their sites, including data on the top referring sites and URLs. This information is indicative of how the site is used and can help managers decide what information should be featured or how navigation might be altered. Many sites also maintain a “Contact Us” function that allows users to send feedback that is reviewed by agency staff. In addition, several Web site administrators indicated that they conduct focus groups and usability testing to better understand user concerns and issues prior to posting information online.

Some agencies have conducted online surveys of users to evaluate site effectiveness. Using either a static survey that appears in the navigation bar or a pop-up survey (or bounce-back form) that might appear at the beginning or end of a session for every 20th user (for example), these surveys often allow greater detail about the demographics and views of Web site users. For example, questions on the Medicare Web site survey asked about the usefulness and comprehensiveness of the information provided, the length of time it took to find information, areas for improvement, and user demographics. The NLM’s MEDLINEplus survey found that over 25% of the site’s users were from other countries and that over half of users were either patients with a specific condition or their family or friends.
Several of those interviewed mentioned the constraints they face conducting user survey evaluation because the Office of Management and Budget (OMB) requires clearance on any survey activity. One interviewee mentioned an effort underway by the Federal Consulting Group to receive generic OMB clearance on a Web site survey that could then be used by all federal agencies. The survey, which is currently being tested by Firstgov, includes 18 questions on topics such as content, navigation, and performance using a 10-point scale.

**KNOWLEDGE MANAGEMENT**

Given the constantly evolving state of health information and services, assuring that information available to the public is accurate and up-to-date is a major task facing federal health Web sites. Many of the sites contain thousands of pages and links to hundreds of organizations, all of which must be maintained. Federal Web site administrators use several strategies in approaching this task.

Some agencies manage their Web sites content through a series of internal clearance steps. The agencies or external contractors develop the content. That information is then reviewed and “cleared” at various levels, with ultimate sign-off by an individual (or set of individuals) that may be located in the communications office or in some other department.

Other agencies have a validation process in which every piece of content is reviewed on a regular basis (with timeframes ranging from quarterly to annually, depending on the material). Some agencies mentioned that they are investigating automatic content management software but are often stymied by its high cost. In some cases, sites include dates on their web pages so users know when it was last reviewed. Other federal Web sites rely on e-mail contacts from outside the agency to trigger a review of outdated materials. Several agencies also mentioned that they used automated link checking services to verify that links are still active.

Administrators of federal health Web sites that use information databases to support their Web sites, as opposed to text-based information, mentioned that the databases made it easier to create knowledge management processes. For example, MEDLINEplus uses a system that electronically tracks every change to the databases underlying the site, allowing multiple and distributed reviewers (such as medical librarians nationwide) to work on the material, while still maintaining centralized oversight.
In talking about the future facing their federal health Web sites, interviewees mentioned their priorities in the coming years, as well as the challenges they face. Many spoke of new types of content or services under consideration—particularly content or services that were more customized, allowed transactions, or addressed particular population groups. Several spoke of anticipated efforts to make their Web sites easier to navigate.

Challenges included better integrating agency Web sites to make them more consumer-friendly, addressing issues of lack of access and low literacy, financial constraints, and encouraging strategic leadership about the central importance of online health information in agency communication efforts.

New Content

Several interviewees mentioned new types of content under consideration on their sites. These included a possible “ask-an-expert” feature that would allow users to submit questions electronically to an expert and receive an answer, more news coverage, more local content about resources available in a user’s geographic area, and more content that might more clearly influence user behavior. Several Web site managers were considering greater use of commercially developed content through licensing (for example a medical dictionary).

Several site officials mentioned translating content into other languages as an area of future activity. Those whose Web sites did not currently include Spanish content mentioned its inclusion as their primary focus—particularly the ability to have an interface that allowed users to see the information in both English and Spanish, thereby allowing, for example, an English-speaking health professional and a Spanish-speaking patient to view the information together. Those who have already developed Spanish-language content, such as MEDLINEplus, were investigating information translated into other languages.

Administrators of portal health sites mentioned several unique activities under consideration. The development of original content in areas not covered by the sites they link to was one area. Incorporating a more evaluative approach to the content accessed through the portal was another. This might result in the portal site’s developing and featuring a “top 10” list of sites delivering information on a particular topic, in addition to providing access to all information on the topic.
Increased Customization and Transaction Applications

Several interviewees discussed efforts to develop Web site approaches that felt more customized by the user. These included packaging information currently scattered throughout the sites into audience-specific information. As indicated above, many sites are already doing this through their segmentation by gender, stage of life, and other factors. Some site administrators mentioned American Indians and Asian Americans as target audiences under consideration.

The ability for users to interact and conduct transactions with federal health Web sites was also mentioned by several of those interviewed. These capabilities might allow a user to self-manage his or her own data, supplying, for instance, preferred addresses for regularly scheduled mailings (perhaps a winter address and a summer address), the language in which the user would prefer to receive materials, or the types of information that he or she would like to receive. Another interviewee mentioned a government-wide future that might allow an individual to enter a new address once into the system and have it shared across government agencies. While many of the transactional activities under federal agency consideration do not necessarily apply to consumer publics (for example, grants management and regulatory activities), online ordering of health publications was mentioned by several agency officials as one that does. Depending on the type of transaction conducted, issues of authentication (you are who you say you are) will need to be addressed. Finally, the ability to more directly interact with users through proactive electronic outreach was also mentioned. Sending out e-mails that “remind” a user about a health promotion topic was one example cited.

Improving Navigation

Increasing federal Web site’s navigational aids and strategies that help users find what they need were mentioned by several interviewees as a future priority. As one interviewee noted, this involved “cutting out steps and irrelevant information” for the user by gathering user information up front and then delivering only that information that is relevant. An example would be learning early in the interaction with a Medicare Web site user that he had end stage renal disease and therefore would not be eligible to enroll in a Medicare HMO. Having search results that include only the benefits a user is eligible for—including those that they may not have thought of—increases the value of the service.
Interviewees also mentioned upgrading the sophistication of Web site search engines as a future priority. One interviewee framed search engine planning efforts by saying, “Here’s my need—bring me the information that addresses my need.” Several people mentioned development of a thesaurus that allows users to plug in multiple words to find the same information.

Many interviewees mentioned the need for greater testing of their sites’ actual usability. While many agencies had used focus groups in the development of their sites, and had conducted usability testing, additional work in this area was cited as a future priority.

CHALLENGES AHEAD

Making Web Sites More Consumer-Friendly

The need for federal Web sites to be better integrated, both from a navigational and visual perspective and from a content perspective, was mentioned by many of those interviewed. Most federal health agencies comprise multiple divisions, bureaus, centers or institutes—each of which conducts a unique set of activities often targeting a discrete set of audiences. In many cases, Web site activities grew from the “bottom up” through agency subunits—with different approaches used to provide information for various publics. This “stovepipe” approach, as several interviewees termed it, can be difficult for online users to navigate—as information may be hard to find or redundant, and navigation protocols may be radically different within a site. However, the organizational visibility and prestige associated with producing online information often makes it difficult for agency subunits to change. As one interviewee noted, “We need more champions for the citizen than for the organization.”

A second result of the way federal health Web sites have evolved over time is that, in many cases, consumers or patients were not originally intended as the audience for the agency’s information and thus much of the material generated was not written for consumers. Many health Web site managers were then surprised when they started looking at who was using their sites and found that consumers and patients had become a large “unintended” audience. While many agencies have adapted and begun to provide consumers with information, this has not been an easy task and remains an ongoing challenge. As one interviewee noted, “Converting information for consumers that wasn’t originally intended for them is not easy.”
A final issue raised by health Web site managers was the tension between a future driven by new information technology (IT) and one driven by an ongoing assessment of users’ needs. According to those interviewed, an IT-driven focus is too often dominant. As one interviewee noted, “most librarians know that you need to turn off all of the graphics and flash.” This “technological seduction” in the words of another interviewee can lead to frustrated or turned-off users. “Just because you can provide a new technology doesn’t mean you should,” said another interviewee. Helping IT departments understand the needs of agency audiences and then using technology to support those needs is a major challenge.

Lack of Access and Low Literacy

Increased reliance on the Internet as a key communications vehicle will raise issues about access to that information. Several interviewees noted that many in this country do not have easy access to computers or to the Internet. The extent to which federal health information and resources are primarily available through the Internet could be problematic for the millions who do not have access.

In addition, the issues of low literacy, which have begun to be generally addressed by consumer health information experts and advocates, also apply when providing information through the Internet. Some Web sites are beginning to address these issues by working with materials that use more visual images and simpler terms. MEDLINEplus provides over 50 interactive health education tutorials using animated graphics and easy-to-read language (http://www.nlm.nih.gov/medlineplus/tutorial.html). AHRQ produced a simple publication titled Ways You Can Help Your Family Prevent Medical Errors that also uses pictures and simple statements (http://www.ahrq.gov/consumer/5tipseng/5tips.htm).

Resources

All of those interviewed were concerned about the ability to receive financial resources to maintain or continue to improve their federal health Web sites. While Web site activities are often viewed by budget staff as less costly than other forms of communications (print, events, etc.), one interviewee felt that her agency’s Web site actually increased the demand for products and services by making them visible to a wider audience. The ability to quickly incorporate newly emerging technologies, to regularly conduct evaluations, and to act on the findings all cost money in an era of tight budgets. What
may result from limited funding is “Web site stagnation” in the words of one of those interviewed, which in the fast-paced ever-changing Internet world, could sideline the site as a resource.

A second expressed concern is the lack of staffing expertise needed to produce high-quality, consumer-oriented health information. Converting nonconsumer information or generating new content for consumers takes special skills not traditionally resident in federal health agency staff. While “home-grown” staff expertise has developed over time and some training has been provided, this remained a challenge mentioned by some federal health agencies.

**Strategic Vision and Leadership**

The last challenge noted in the interviews was the need for federal leadership and vision about the importance of the Internet as a major communication vehicle for reaching consumer and patient audiences now and in the future. Recognizing that online health information has generally evolved piecemeal since the mid-1990s, the time is now, in the view of many of those interviewed, for more critically examining the role of online health information in the context of overall agency goals. As one interviewee noted, “We need a strategic vision of what we want to accomplish versus having a conglomerate of sites.” It also may mean elevating the importance of a Web presence from a “novelty” to a “mission critical” component of federal health agencies.

As one interviewee noted, this strategic thinking occurs in the context of broader changes in the health landscape—both in terms of the increased interest in and necessity for consumers to play a larger role in their own health care decisions and in the dizzying pace of technological change. As a result of economic shifts, education advances, media coverage, and other factors, citizens are willingly and, in some cases, unwillingly expected to be better health care consumers. Their need for publicly available, accurate, updated, accessible information will be great.

At the same time, the rapid pace of technological change offers the opportunity to think about using the Internet in new ways to provide health information and services to the public either directly or through intermediaries. New applications that focus on health behavior change, more customized decision support, health performance measurement, or other types of “e-health” activities could represent a next generation of federal online health activity. Certainly, consideration of the
accompanying risks, such as privacy, security, and political trade-offs, as well as the more fundamental discussion about the relative roles of the government and the private sector in some of these activities, would also need to occur. With leadership and vision, however, a meaningful discussion could take place within and across federal health agencies about the answer to the question posed by one of those interviewed: “What do we really need to do to improve health using this technology?”

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APPENDIX I: FEDERAL AGENCIES INTERVIEWED

Agency for Health Care Research and Quality (AHRQ)
Centers for Disease Control and Prevention (CDC)
Centers for Medicare and Medicaid (CMS)
Department of Health and Human Services (DHHS)
Food and Drug Administration (FDA)
General Services Administration (GSA)
Health Resources and Services Administration (HRSA)
Indian Health Service (IHS)
National Institutes of Health (NIH)
National Library of Medicine (NLM)
Office of Disease Prevention and Health Promotion (ODPHP)
Substance Abuse and Mental Health Services Administration (SAMHSA)