

# Strategies to Improve Consumer Health Information Services

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*Abstract: Consumer health information is important in two respects. It helps individuals improve their own health and creates pressure on the healthcare system to produce higher quality care. Initiatives to strengthen consumer health information services are underway in many public and private-sector organizations nationwide. This paper describes some trends in the field and opportunities to spur further progress nationally and at the community level over the next few years.*

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Throughout the history of American medicine until the late 1990s, public access to medical information was very limited. Detailed information about diseases, treatments, and drugs lay almost entirely in the province of clinicians and medical libraries. That longstanding paradigm is undergoing a major transformation. Americans are gaining access to vast amounts of health information and are being urged to use it proactively to improve their care. Prescription drugs are now heavily advertised on television.<sup>1</sup> News media carry frequent reports about advances in biomedical technology. Experts warn of widespread errors in medical treatment. Most Americans now have access to the Internet, and millions are using it to get information from thousands of health-related Web sites.<sup>2</sup> With consumer out-of-pocket costs rising and chronic diseases becoming more prevalent, the public's appetite for health information will undoubtedly increase.

Given these trends, it is timely to assess how well information services are meeting consumer needs. Are people getting the information they need when they need it from sources they trust? Currently, many "information seekers" are frustrated by information overload and confused about whether or not the information they find is relevant, complete, and credible. Many

people who are not now "information seekers" are deterred from getting and using the information they need by barriers to access, such as lack of information that is comprehensible and well-targeted to address their personal concerns.

Developing new information strategies to address these problems is vitally important to achieving national goals for better health, quality of care, and quality of life. The recent Institute of Medicine report *Crossing the Quality Chasm* calls for action to address widespread failures of the healthcare system to give individuals the information they want and need. For example, people with chronic diseases are at high risk of developing serious and costly complications if they are not well informed about how to manage their conditions on a daily basis. Treatment of chronic conditions and associated complications now accounts for the majority of healthcare costs nationally.<sup>3</sup> The federal report *Healthy People 2010* underscores the urgency of developing better health communications. It sets as a national goal to "use information strategically to improve health outcomes."<sup>4</sup> National strategies to strengthen consumer information services need to be a key element of national efforts to improve health status.

## **PROGRESS IN THE FIELD**

Recent experience and research in the field are helping to clarify consumer needs and preferences concerning health information services. For example, many consumers want advice in addition to having reliable information about their options when they make important health decisions. Ideally, services should help users connect to trusted advisors (e.g., physicians, voluntary health agencies, and individuals coping with similar problems) as well as providing information that is well tailored to individual

circumstances. Appendix 1 outlines some attributes of health information services that experts suggest are highly desirable to meet consumer needs.<sup>5</sup>

To many consumers, the concept of having better information and assistance in choosing among health plans, providers, and treatments is foreign. Researchers who convened 22 consumer focus groups to examine the concept concluded that having such decision support would be for many consumers “something they will not know they have been missing until it arrives.”<sup>6</sup>

Because the concept is so new, expecting consumers to seek and use health information proactively requires that more groundwork be laid with the public to explain what information is important to consider, where to find it, how to get assistance in understanding and interpreting it, and how it will benefit them directly in their lives.<sup>7</sup>

Some public education efforts of this type are occurring. The recent federal campaign to inform the public about the “1-800 Medicare” information line is an excellent example from the public sector. Another example is the ongoing National Diabetes Education Program launched by the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) in 1997. It involves 200 collaborating organizations nationwide.<sup>8</sup> Similarly, the National Health Council is coordinating a public education campaign with its member voluntary health agencies promoting the message, “It’s your health. You call the shots.” The campaign materials give people practical advice about how to communicate better with providers. Direct-to-consumer advertising for prescription drugs is a prime example of how effectively promotional campaigns can motivate consumers to take ac-

tion when the campaigns are well targeted, multi-dimensional, and sustained.<sup>9</sup>

Many public and private-sector organizations (e.g., insurers, provider organizations, consumer groups, foundations, and public sector agencies) are sponsoring major initiatives to strengthen consumer health information services. For example, some insurers and provider organizations now offer consumer-focused Web sites, preventive care and disease management outreach programs, and peer support programs for patients and caregivers in their target populations. Some of the new peer support programs include meetings in person or online, introducing patients to “buddies” who have similar medical experiences, chat rooms, bulletin boards, customized Web sites with online tutorials and links to other relevant Web sites, referral information to local resources, e-mail access to experts and peers, and computerized care management support tools. Some purchasers give their beneficiaries self-care handbooks (such as those from Healthwise, Inc.) that are linked to Web sites for more in-depth information.<sup>10</sup>

To help purchasers and consumers choose among competing health maintenance organizations (HMOs), the National Committee on Quality Assurance (NCQA) accredits HMOs and offers annual health plan report cards.<sup>11</sup> NCQA, the Foundation for Accountability (FACCT), Medicare, the California HealthCare Foundation, Pacific Business Group on Health, and others are experimenting with reports and online tools to help consumers interpret qualitative information about HMOs and, in some instances, providers (e.g., hospitals, nursing homes, and physician groups). This brief sampling of consumer information initiatives could be multiplied many-fold.

Nonetheless, there are important development priorities nationally that various

public and private-sector organizations cannot be expected to address individually. Either they lack the resources or cannot justify the investments based on their organizational missions and financial interests. To address these priorities, additional strategies are needed that can be shaped and funded collaboratively with the organizations that provide consumer information services.

## NATIONAL STRATEGIES

Several strategies stand out as significant and promising opportunities to spur progress over the next few years. They involve initiatives to (a) facilitate public access to excellent information resources that are responsive to individual needs, (b) engage physicians in guiding patients to appropriate information tools, (c) give consumers better information to help them select physicians and other providers, and (d) combine innovative information strategies in community experiments designed to achieve targeted health outcomes.

### **Strategy 1: Facilitate public access to excellent health information resources that are responsive to individual needs**

Consumers and providers nationwide could benefit greatly from having easy access to a resource base of credible, effective consumer health information in the public domain. It would give consumers the choice of a consistently reliable starting place to find information on a wide variety of health topics for themselves, family members, and others, regardless of their physician relationships or insurance coverage. It would give clinicians a simple means of prescribing free patient tutorials, decision support information, and self-management tools that have proven to be effective. Health organizations could link to this national

resource base and draw useful information from it into their own branded Web sites. The resource base would be, in essence, a national "information utility" serving the public and the healthcare community.<sup>12</sup>

The National Library of Medicine (NLM) is a natural candidate to manage such a resource base. NLM is the largest medical library in the world and is an integral part of the National Institutes of Health (NIH). Part of NLM's mission is to translate advances in biomedical knowledge to the public and clinicians. Having NLM organize consumer health information resources for online access by the public fits well with that translation agenda. NLM has already assembled and licensed a variety of high-quality consumer-focused health information resources, now available through its *MEDLINEplus* Web site ([www.medlineplus.gov](http://www.medlineplus.gov)). The site is popular, drawing approximately 6 million users and 60 million page hits in 2001, although it is not yet well known to the public or even among healthcare professionals. User survey results indicate high levels of satisfaction, and *Consumer Reports* recently deemed the site the best place for consumers to start Web searches on medical information.<sup>13</sup>

The envisioned national resource base would provide in-depth information on hundreds of medical conditions and include a wide array of materials to meet the needs of diverse populations. The information retrieval system would incorporate expert systems to provide quick access to information that is well tailored to individual user needs. The information would be continuously updated to reflect advances in medical knowledge and the site would be continuously refined as new information technology and communication methods evolve. For example, a video library could be developed with on-demand access provided through broadband technology. To promote widespread use of the resources, a

public education campaign would be required to inform the public about the resource base, explain how to access it, and promote the benefits of doing so.

Although few Americans over age 60 use the Internet yet, it would be a mistake to underestimate their potential use of a sophisticated, online information resource base in the public domain. About 52% of individuals aged 50 to 55 already go online. The Pew Internet and American Life Project forecasts a “silver tsunami” of Internet use by this age cohort as they retire.<sup>14</sup> Research has shown that underserved populations, including elderly and low-income populations, are very interested in and can benefit from using technology such as the Internet to address their health concerns.<sup>15</sup> For example, the Comprehensive Health Enhancement Support System (CHESS)—which gives people access to customized Web sites and online connectivity to experts and peers—has been used successfully by elderly and low-income people to help them cope with various conditions (e.g., diabetes, breast cancer, and Alzheimer’s disease).<sup>16</sup> Public libraries, schools, and other community facilities can serve as points of access for individuals who do not have computers at home or at work.<sup>17</sup>

A critical component of improving public access to health information is to develop new resources in languages other than English and in media other than print text. Meeting the health information needs of diverse populations goes to the heart of public policy goals for reducing health disparities. Many people who are at high risk of health problems are not highly literate in English. Some of the newer educational resources now available on the Web hint at the potential to reach these populations. Newer tutorials target specific subpopulations; combine print, audio, and video communication modes; and incorporate user-friendly features, such as choice of subtopics

as well as control over the pace and order of viewing them. One example is a set of video clips on breast cancer topics by and for women who are deaf. It features women signing to one another (their principal language) as well as voice and print subtitles. In addition to being on a Web site, the video has been aired on television more than once because of its usefulness to the population served.<sup>18</sup> Many more people are likely to use health information when they can access it on-demand through new media (e.g., archived video clips and web-casts) featuring people of their own ethnicity discussing their specific health concerns in their own languages.

Development of such resources could be accelerated through increased funding and collaboration among organizations with shared interests. If one or more government entities, foundations, or other sponsors spearheaded the effort, it is likely that they could leverage support from medical specialty associations, pharmacy benefit managers, purchasers, disease management companies, pharmaceutical sponsors, voluntary health agencies and others to develop a broad-based set of resources. All of these organizations could contribute to funding population needs assessments, creation of resources, promotional efforts and evaluation of their effectiveness. The NLM could integrate the various types of communication media and tools developed in various languages into its information retrieval system.

### **Strategy 2: Engage physicians in guiding patients to appropriate information tools**

One of the best ways to encourage consumers to use health information more proactively, and to assure that it is relevant and of high quality, is to engage their physicians in supporting the effort. Recent survey

results show that more than 70% of consumers have a high degree of trust in their physicians.<sup>19</sup> Physicians are therefore extremely well positioned to help patients and caregivers interpret health information and steer them to appropriate sources of information to help them understand and cope with their conditions, make more informed choices about treatment, and improve their self-care. However, many consumers report that their physicians do not provide them with adequate information, and physicians reportedly make very limited use of new information technologies that could be tapped to help educate and support their patients.<sup>20</sup> Patients often leave physician offices with only the memory of what they were told, possibly a prescription, and, sometimes, written instructions or a brochure about their condition.

Given how influential physicians are in affecting patient behavior, enlisting their support in referring patients to additional sources of information is extremely important. It would be useful for national physician organizations to take the lead in this area. Research and experimentation are needed to identify system changes that would lead physicians to refer patients to information resources. Physicians and their staffs need to be informed about available resources, confident about their usefulness, and able to make referrals easily. Physicians currently face some of the same difficulties that patients do in dealing with the proliferation of consumer health Web sites and evaluating content quality. One useful national initiative to help overcome this obstacle in the short term would be to educate physicians about *www.medlineplus.gov*. Ideally, physicians will soon have automated support systems for prescribing relevant information to patients as part of their normal practices (such as giving physicians who access drug information through handheld devices prompts suggesting Web site

locations to prescribe for their patients). Research is also needed to examine how market forces and financial incentives can be structured to support physicians' guiding their patients to appropriate information sources and encouraging their use.

### **Strategy 3: Develop better information to help consumers select physicians and other providers**

Consumers need more qualitative information on physicians and other providers in order to make well-informed choices and to help fuel providers' efforts to improve quality of care. At present, most consumers have difficulty finding reliable data regarding even disciplinary actions taken against individual providers at state levels, much less data on measures of clinical practice or patient satisfaction.

As we are seeing in the education field, building robust performance measurement systems is controversial and difficult to do well. In the health field, such systems need to use significant, defensible measures that consumers and physicians find useful. One innovative model is the Provider Recognition Program developed by the American Diabetes Association (ADA). Physicians who want to participate submit medical records documenting how they treat patients with diabetes. The physicians who meet program standards receive certificates for display in their offices and their names are promoted by the ADA through its Web site to consumers who seek guidance in provider selection. The standards are based on clinical performance measures that were developed by experts as part of a collaborative project known as the Diabetes Quality Improvement Program that is sponsored by the Centers for Medicare and Medicaid Services, ADA, FACCT, NCQA, the American Academy of Physicians, the American College of Physicians-American Society of

Internal Medicine, and the Veterans Administration.<sup>21</sup>

Developing better information on physicians and other providers is a major undertaking, similar to the undertaking by NCQA and others to build the HMO accreditation system and comparative reports on HMO performance over the past decade. The effort will require similar support from major purchasers, insurers and physician leaders to develop measures, standardize and aggregate data, and overcome fears and opposition. Medicare could play an important role along with other purchasers in promoting system development. In addition to its very large database of provider claims, the program has a large population of beneficiaries who could offer valuable feedback on their treatment experiences. Medicare is already offering comparative data on HMOs, nursing homes, and renal dialysis centers.

Many industry leaders now view consumer access to data on physicians and other providers as a necessary corollary to expecting consumers to take more personal and financial responsibility for decisions about their care. New communication and information system technology are beginning to make data aggregation and analysis more feasible and cost effective than in the past. Creative efforts by leaders from the public and private sector are needed to steer progress in this direction.

#### **Strategy 4: Combine innovative information strategies in community experiments designed to achieve targeted health outcomes**

Many new information services have been developed in separate organizational silos, and some of the new approaches that have been developed collaboratively at the national level have not been well funded

for implementation and evaluation at local levels. The idea of investing more in community experiments is that, by fostering collaboration among local organizations to address specific community health problems, we may reach a “tipping point” in terms of achieving greater impact on consumer empowerment and quality improvement in areas of concern than has previously been possible.<sup>22</sup> Well-designed experiments at the local level can yield invaluable insights about information resources and communication methods that would be useful to many organizations across the nation that work with similar target populations and health issues.

Local leadership and collaboration are critical to designing solutions to community health problems. Local solutions may entail new combinations of communication techniques, health promotion strategies, national and local information resources, and quality improvement tools developed in the public and private sectors. They may involve new information flows among local organizations. Availability of more funding for experimentation could spark productive new collaborations, for example, among healthcare providers, consumer organizations, local businesses, government agencies, and television and radio channels.

At the federal level, sponsors for such experiments could include CDC, NIH, the Agency for Healthcare Research and Quality, and the Centers for Medicare and Medicaid Services. Any of these entities could support projects or co-sponsor them on the model of the National Diabetes Education Program. From the private sector, foundations could provide invaluable leadership and funding in this area. Drug companies and insurers, which have expertise in communications and large investments in consumer and physician relations, might also be persuaded to partner in such experiments. The experiments could be focused on high-risk populations and

health problems identified in *Healthy People 2010* as critical targets for improvement.

## FEASIBILITY AND FUNDING

Although funding constraints loom as potential obstacles to implementing major new national initiatives, each of the strategies described can be approached through modest initial investments in feasibility testing and “proof of concept” demonstrations. Decisions about major investments can be reserved until more is known from detailed needs assessments and pilot tests. The strategies outlined—improving public access to excellent information resources, supporting physicians in prescribing information, giving consumers better data on physicians and other providers, and combining health information strategies in community-based experiments—all build on recent advances in the field and address important development priorities to improve health and health care. Because the strategies are complementary and supportive to organizations that are involved in the field, pursuing the strategies in tandem and collaboratively is desirable. They offer a rich opportunity to advance effective uses of consumer health information nationwide.

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## ENDNOTES

1. Expenditures for direct to consumer drug advertising exceeded \$1.85 billion in 1999, an increase of more than 230% from 1997, when advertising on television began. See PhRMA Annual Report 2001-2002, 13, <[www.phrma.org/publications/publications/annual2001/](http://www.phrma.org/publications/publications/annual2001/)> (19 October 2001).
2. “Internet Access Continues to Grow but at Slower Pace,” Harris Poll #60, 11 October 2000, <[www.harrisinteractive.com/harris\\_poll/index.asp?PID=122](http://www.harrisinteractive.com/harris_poll/index.asp?PID=122)> (19 October 2001). Survey results suggest nearly 100 million Americans used the Internet to get health information in 2001. L. Landro, “Getting Reliable Health Information,” *Wall Street Journal*, 12 November 2001.
3. Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*, (Washington, D.C.: National Academy Press, 2001), 27.
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5. Many of the service descriptors identified in Appendix 1 were identified by experts at a meeting on Consumer Health Information Strategies that *Health Affairs* and the Health Insurance Reform Project sponsored in November 2001. See also “The Personal Health Dimension,” in National Committee on Vital Health and Statistics, *Toward a National Health Information Infrastructure: Interim Report* (Washington, D.C., June 2000), <[www.ncvhs.hhs.gov/NHII2k/Report.htm#personal.htm](http://www.ncvhs.hhs.gov/NHII2k/Report.htm#personal.htm)> (10 January 2002); and Research Council Committee on Enhancing the Internet for Health Applications, *Networking Health:*

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10. See "Healthwise Self-Care Guides," <[www.healthwise.org/p\\_self-care.html](http://www.healthwise.org/p_self-care.html)> (10 January 2002). These guides have been distributed to millions of households by public and private-sector sponsors.

11. "NCQA's Health Plan Report Card," <[hprc.ncqa.org/](http://hprc.ncqa.org/)> 10 January 2001.

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## **Appendix 1**

### **Desirable Attributes of Consumer Health Information Services**

- Encourage individuals to be proactive in managing their health care and help them locate relevant information and assistance.
- Feature practical advice on how to navigate the healthcare system.
- Answer the questions people have when their information needs arise.
- Accommodate differing communication needs and norms (for example, not just English text).
- Address health and coping issues that individuals and their families face in various phases of their lives—including independent living, long-term care, and end-of-life.
- Give consumers access to their medical records anytime from anywhere and ability to authorize access by others.
- Promote information sharing among individuals, clinicians, families, and caretakers.
- Offer easily accessible and understandable information from sources people trust.
- Promote access to experts who can help consumers understand their choices and interpret the relevance of information to their concerns.
- Consider values and preferences (for example, acceptability of side effects) as well as evidence of clinical effectiveness in presenting information about alternatives.
- Include expert systems that will customize consumer risk profiles, preventive care alerts, and information about treatment options to account for individual factors such as genetic predisposition and medical history.
- Offer standardized performance data to help consumers select providers and plans.
- Design information services based on detailed needs assessments for targeted subpopulations and address obstacles to access (for example, computer access and training).
- Evaluate and refine the services systematically to meet defined objectives.