Chapter 2. Mapping Diversity to Understand Users' Requirements for e-Health Tools

Introduction

It is commonplace to observe that the United States is a diverse society and becoming increasingly so. Diversity has many dimensions including, but not limited to, cultural, economic, educational, and experiential factors (IOM, 2002). The vision for consumer e-health tools proposed in the Preface and described in the introduction (Chapter 1) emphasizes the importance of diversity and user-centric approaches.

At heart, the matter of consumer engagement with e-health tools is an issue of human communication mediated by technology, and the principles of effective communication practice must inform the design and use of tools. The strategies needed to realize the vision must be grounded in solid research on population diversity, communication, and ways that user characteristics will affect the uptake of consumer e-health tools by new groups. A more complete picture of users and the factors influencing their use of e-health tools is critical not only to the design of the tools themselves but also to meaningful metrics used to assess the tools, their dissemination, and their effects.

The need for a deep-level understanding of individual, population, and systemic factors affecting e-health tool use is acute in the context of national discussions to eliminate health disparities and improve health literacy (IOM, 2003, 2004). The health disparities and health literacy agendas make clear that critical systemic factors affect the ways people act in relation to their own health and interact with the healthcare system. These influences and their variations from person to person and from group to group have yet to be fully identified and described, and they are not adequately captured by traditional public health models and explanations that use demographic factors as the basis for communication interventions (IOM, 2002).

Digital and information disparities should be a matter of great concern for public health and medicine because many of the same segments that lack adequate Internet access and appropriate health information also have the highest risks of developing, or already have high rates of, chronic diseases (HHS, 2000). Appendix 4, A Comparison of Internet Use and Health Status of Populations That Experience Health Disparities, presents data on health disparities and Internet access. Research on consumer attitudes, perspectives, requirements, and behavior is critical to inform policies that put greater responsibility for personal health management on these at-risk population groups.

Apart from consumer surveys on trends in Internet use, little research to date has analyzed the individual and population factors most relevant for consumer e-health

tools, particularly in light of personal health management requirements. Findings of this study that were culled from the scientific literature and interviews with e-health tool developers and leading observers in the field confirm that little consumer e-health research is available, particularly at the subpopulation level. Such research is necessary to inform projections of who will use e-health tools in general, or who will use specific tools, and how the use of these tools will affect their perceived and objective health status (see Chapter 3 and Appendix 1).

For the most part, the research indicates *either* who is using the Internet for health-related purposes, primarily health-information seeking, *or* how participants in research studies react to specific e-health tools. The often-overlooked elements in the overwhelming number of studies are the human factors and communication dimensions of e-health tool use. Perhaps because of the nature of online communities and the amount of personal information revealed by users, more studies in this category than any other examined in this report have explored questions of identity, beliefs, motivation, emotional and psychological states, and communication styles. (See Chapter 3.)

Even though demographic factors often provide the basis for the targeting of public health interventions, the interventions themselves rely heavily on influencing communication variables and processes as a means to produce behavior change or other outcomes. The Institute of Medicine's (IOM's) Committee on Communication for Behavior Change in the 21st Century questions demographic factors as reliable

guides to understanding how individuals and groups engage in and are affected by information and communication (IOM, 2002). The Committee recommends that demographic factors be used to identify the distributions of health benefits and broad intergroup differences, but that these factors *not* be used as the basis for health communication programs and interventions. The Committee supports an approach that considers the full range of communication factors, including cultural processes, access to information and technology, and life experience.

This chapter uses that IOM recommendation as a starting point to outline a user-based approach to e-health tool design and dissemination. Some of the factors examined are demographic; others are psychosocial and communication-related. Collectively, they create a complex picture of the influences and elements that must be mapped as part of a consumer-centric analysis of the e-health tool phenomenon. Each of these factors may be more or less critical depending on the population and needs being addressed by the tool and the context in which it will be used. These factors, along with ones that have yet to be identified, provide the components for new models and strategies to reach and engage all sectors of the population and enhance the effect of a broad range of tools.

THE HEALTH LITERACY CONSTRUCT AND ITS RELEVANCE FOR E-HEALTH

Health literacy is emerging as a powerful construct for identifying the environmental and human factors that influence the

ways in which people interact with health information and the healthcare system. Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004; HHS, 2000). Literacy skills include not only reading and writing prose but also numeracy and use of different types of documents, such as forms. Individual and population health literacy is dependent on a mix of individual and systemic factors, including the communication skills of both laypersons and professionals; lay and professional knowledge of health topics; cultural factors; the demands of the healthcare and public health systems; and the demands of the situation or context. According to recent reports from IOM and the Agency for Healthcare Research and Quality (AHRQ), large amounts of existing print health information are too complex for approximately half of all adults in the United States to understand and use (Berkman, DeWalt, Pignone, et al., 2004; IOM, 2004).

Health literacy is an emerging area of study, and there has been limited reliable research on its many dimensions (IOM, 2004). Estimations of group-level health literacy capacities, for the most part, have been based on two national studies of the population's literacy skills and numerous small studies of either literacy or health literacy skills (IOM, 2004; Kirsch, Jungeblut, Jenkins, et al., 1993; National Center for Education Statistics, 2005).[1] One

recent study did attempt to pool numerous small studies using multiple health literacy assessments and found that these pooled estimates were similar to the findings from the national literacy data (Paasche-Orlow, Parker, Gazmararian, et al., 2005).

Literacy skills are unevenly distributed across the population, similar to education level, income, health status, and Internet access. Literacy rates are lower among older adults and persons of lower education and income (Kirsch et al., 1993; National Center for Education Statistics, 2005). Literacy capabilities affect people who speak English as well as other languages, may impede communication of health prevention messages, and diminish the ability to participate in interventions. Literacy skills also affect how people, particularly those in underserved populations, use the Internet (Baur, 2005; Echt and Morrell, 2003; Zarcadoolas, Blanco, Boyer, et al., 2002).

Individual capacities, however, do not appear to be the most important factor in limited health literacy in a population. Health literacy problems exist in large part because the systems that provide health information and services are unfamiliar and complex, which makes it difficult for many people to understand and use them effectively (IOM, 2004; HHS, 2003). The information that health professionals have created is jargon-filled, technical, and dense; the forms and paperwork are confusing, complicated, and lengthy; and the care process and systems are cumbersome and oriented to professional requirements. As a result, few individuals are likely to ever have all the capacities needed to understand and navigate systems

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1 The 2003 National Assessment of Adult Literacy from the U.S. Department of Education includes items on health literacy that will be used to compose health literacy scores, but the data had not yet been released when this report went to press.

Example of literacy and cultural factors relevant to e-health tools

The study subjects for our project live in a community where the level of educational achievement is low. As a result, literacy has been one of the most important characteristics of this audience affecting the design of our problemsolving e-health tool. Many of the students cannot read at grade level and have poor comprehension skills. Thus, we have had to pay particular attention to the language and reading level that our online problems feature. Simple words and short sentences are essential. If this characteristic were overlooked, then our tool would have been useless to its intended audience. . . . In addition, many of our students come from immigrant families where English is not the primary language spoken at home. We have had to recognize that some students cannot read English well, and this must be considered in designing an e-health tool that reaches all of its intended audience. Finally, minority populations often have cultural beliefs or practices regarding asthma that influence their disease management choices. We have talked with community members about these culturally based ideas and have tried to incorporate them into our problemsolving cases in order to make the experience more relevant to them.

Understanding the characteristics of our study population enables us to determine whether our tool is able to generate an authentic assessment of our audience's asthma knowledge and management skills. . . . [W]hen large numbers of students are not getting a problem right, it may not always mean that they are not capable. The appreciation of our audience's reading challenges enables us to realize that it can also mean that our tool is not working and has to be adjusted. This feedback from our target audience enables us to evaluate and perform ongoing refinement of the e-health tool. (A. Casillas, personal communication, October 22, 2003)

as they currently exist. In other words, system design has created many health literacy problems, and system design must be altered to address the problems.

It appears that many of the health literacy issues that have been identified in the print environment are being transferred to the electronic arena. As noted in Chapter 3, research suggests that many Internet sites and their content are created in a style and vocabulary too complicated for many segments of the public, erecting a barrier to understanding and communication (Graber,

Roller, and Kaeble, 1999; RAND Health, 2001; Zarcadoolas et al., 2002).

The commentary from Adrian Casillas, M.D., highlighted in the box above, illustrates how health literacy factors play out in the design of a consumer e-health tool. It also illustrates how literacy and cultural factors are not the same, even though they may affect the same user groups; they need to be addressed with different remedies. The vignette exemplifies the conscious and ongoing effort required of researchers and developers to understand

the meaning of tools and content from the intended users' perspectives. Dr. Casillas describes the thinking behind his Los Angeles-based public health work with children with asthma, 60 percent of whom are members of Mexican and Central American immigrant families.

The Key Concept of Meaningful Access

To use e-health tools, people obviously must own or have access to technology, including hardware, software, and Internet connections. This type of basic or physical access to technology, however, has been found to be insufficient to promote or sustain technology use among some groups of users (One Economy Corporation, 2004; The Children's Partnership, 2000, 2002, 2003). Users may not have the skills or resources they need to use technology; diagnose and solve technical problems; afford continuous service charges; or locate and understand content (Eng, Maxfield, Patrick, et al., 1998). The lack of physical access, skills, or resources creates multiple obstacles that must be identified and overcome.

Consequently, researchers and practitioners working on issues of technology access have developed the concept of "meaningful access" to encompass equipment, Internet connections, skill development, ongoing technical support, and appropriate content, all of which have bearing on the issue of a "digital divide" in society (HHS, 2003). Similarly, the health literacy construct unites the issues of capacities, access, and understanding, although it has rarely been applied to the analysis of technology use (Baur, 2005). Both concepts highlight the importance of understanding users' capacities and characteristics in light of systemic barriers that inhibit the full exercise of capacities.

Unequal access to the Internet and related technologies has been characterized as a "digital divide"; naturalistic trends toward broader access across the population and targeted interventions to increase access are described as progress toward "digital inclusion" (HHS, 2003). The health objectives in *Healthy People 2010* include an objective to increase Internet access in the home, confirming the critical nature of Internet access for the health of the entire population (HHS, 2000). Considerable progress has been made since the late 1990s, when the U.S. Department of Commerce report, *Falling Through the Net,* called the digital divide "one of America's leading economic and civil rights issues" (U.S. Department of Commerce, 1999). Nevertheless, segments of the population— primarily defined in existing studies by income, age, language, and disability—still lack access when compared to the segments with the highest rates; income is a key factor in the divide.

Table 1 reports the most current Census Bureau data on Internet access at the total and subgroup levels, using *Healthy People 2010* categories and the 1998 baseline data for the *Healthy People* Internet access objective. Since the Census findings reported in Table 1, survey research from the Pew Internet & American Life Project indicates that broadband is rapidly becoming the new

Table 1. Households With Internet Access

	Baseline, 1998[a]	2003[b]	Broadband Access, 2003[b]
Total Population			
Total population	54%	59%	23%
Race and Ethnicity			
Asian or Pacific Islander	36%	63%	34%
Black or African American	11%	45%	14%
White	30%	65%	26%
Hispanic or Latino (of any race)	13%	37%	13%
Gender (head of household)			
Female	15%	59%	22%
Male	20%	58%	24%
Education Level (head of household)			
Less than high school	5%	16%	6%
High school graduate	16%	45%	15%
At least some college	31%	69%	24%
Geographical Location			
Urban (metropolitan statistical area)	28%	59%	No data available
Rural (metropolitan statistical area)	22%	57%	No data available
Family Income			
	1997[c]		
Less than $15,000	30%	31%	8%
$15,000-$24,999	37%	38%	9%
$25,000-$34,999	49%	49%	13%
$35,000-$49,999	60%	62%	19%
$50,000-$74,999	72%	72%	28%
$75,000 or greater	81%	83%	45%

[a] Source: CDC Wonder. *DATA2010. . . the Healthy People 2010 Database.* Focus Area 11.1. January 2006 edition. *http://wonder.cdc.gov/*. Centers for Disease Control and Prevention. Accessed February 14, 2006.

[b] Source: U.S. Department of Commerce. 2004. *A Nation Online: Entering the Broadband Age.* *www.ntia.doc.gov/reports/anol/NationOnlineBroadband04.htm*. Accessed October 12, 2005. Note: The survey is conducted by household, and the data are reported as Internet access from any location by the survey respondents.

[c] 1997 data source: U.S. Department of Commerce. 2002. *A Nation Online: How Americans Are Expanding Their Use of the Internet.* *www.ntia.doc.gov/ntiahome/dn/nationonline_020502.htm*. Accessed March 24, 2006.

standard at the same time income divisions between broadband and non-broadband users become sharper. Total population use of broadband technologies increased to 53 percent by mid-2005; however, 71 percent of Internet users in households with annual incomes of $75,000 or higher have broadband access, whereas 42 percent of Internet households with annual incomes below $30,000 have broadband (Fox, 2005a).

As noted above, the question of access is not simply a matter of having a computer and Internet link; "meaningful access" emphasizes the factors involved in achieving genuine digital inclusion. For millions of Americans, access problems have more to do with their ability to use digital technology and the relevance and appropriateness of the information resources available to them than with their having the right equipment. These other aspects of access are gaining in importance as explanatory factors for the causes and consequences of differences in Internet use and interest among different population segments. A few studies that have examined the role of content, applications, skills, and technical support in generating and sustaining user interest found that some population segments, such as those with low income or limited English proficiency, have limited choices of relevant content (The Children's Partnership, 2000, 2002, 2003).

The most complete approaches to providing access for diverse user groups, therefore, address not only equipment and Internet access but also skill development, ongoing technical support, and appropriate content. A report from the Kaiser Family Foundation expresses the same ideas by distinguishing between *quantity* and *quality*

in Internet access (2005). Being connected to the Internet has little meaning in itself if users cannot find relevant content and services. Specific aspects of meaningful access related to audience characteristics are discussed below in this chapter, and Chapter 3 explores the subject in light of existing research on the appropriateness of content.

Although national surveys of Internet access and use provide little detail on the public's perceptions of technology, some findings suggest diverse attitudes toward, and likely capacities with, technology. Although Internet penetration has increased to its highest levels yet, about 25 percent of the population are not online, primarily because they do not have a computer (University of Southern California [USC] Annenberg School Center for the Digital Future, 2004). Studies suggest that cost is only one obstacle, and not always the most important one, to computer ownership and Internet use. The USC Digital Future study found that only 9 percent of respondents not connected to the Internet reported the cost of technology as the reason. An additional 24 percent reported that they had no interest in being on the Internet, and another 18 percent said they did not know how to use the Internet (USC Annenberg School Center for the Digital Future, 2004).

A small study in San Diego, California, found that psychosocial factors, such as embarrassment at not knowing how to use a computer, were more important than cost in explaining why low-income residents did not purchase computers or were not learning how to use computers at local community centers (Stanley, 2001). Moreover, in this same study, residents reported ownership of other types of

technology, such as DVD players and cell phones, which suggests that their concerns were specifically with computers and not technology in general. Research from the Pew Internet & American Life project supports this finding with data showing that technology gaps by racial group and age are not as great for cell phones as for computers (Fox, 2005a).

As noted in the preceding health literacy discussion, a few small studies suggest that persons with limited literacy skills are likely to be among those who do not know how to use the Internet without training and support. The U.S. Department of Education investigated associations among literacy skills, Internet access, and computer use for the first time as part of the 2003 National Assessment of Adult Literacy; results will be released in the second half of 2006 (see *http://nces.ed.gov/naal/*).

Access to Internet-ready devices such as cell phones and Personal Data Assistants (PDAs) can remedy the lack of a computer. However, the attitude that Internet access is not necessary for daily life may itself become an important source of social division, according to Jeffrey Cole, Director of the USC Annenberg School Center for the Digital Future. He notes that people who live daily life disconnected from the Internet may face real costs—financial and social—not simply inconveniences: "People who do not want to perform those chores (pay bills, send letters, make appointments, and so on) online will find it increasingly difficult and expensive to avoid doing so" (Cole, 2004).

As an increasing number of health plans, employers, and healthcare providers develop Internet-based resources, their beneficiaries, employees, and patients will have fewer real choices about receiving information and services in a nondigital form. Beneficiaries, employees, and patients who do not have Internet access or choose not to use it will find that either they do not have access to vital information and services or they have to rely on intermediaries who will use these technologies on their behalf. The emergence of broadband as a new standard for connectivity and the dependence of multimedia applications, including most e-health tools, on broadband are already creating additional disparities. Broadband makes it more likely that people will use the Internet and for longer periods, which are requirements if people are going to incorporate e-health tools into their routines.

Learning more about the one-quarter of the population who may become isolated by their attitudes toward digital technologies and the options that will be required to continue to serve them is an emerging research and policy issue. Intermediaries or "infomediaries" have been suggested as a solution for some users who do not want to seek out information themselves or use technology directly; this strategy assumes, however, both that the intermediaries have the necessary access and skills and that they are available when and where users need them. These assumptions raise multiple issues for policymaking that future studies should address.

User Behavior and Health Information-Seeking

Although health is only one reason people use the Internet, approximately 95 million American adults have used it to find health information, most to seek information on a specific disease or medical problem (Fox, 2005b). About one-half of Internet users accessed healthcare information in 2004 (USC Annenberg School Center for the Digital Future, 2004). Experienced Internet users (those with 6 or more years of experience) are far more likely to have used the Internet as a source of health or medical information in the last year than new users (those with fewer than 2 years of experience) (Fox, 2005b; USC Annenberg School Center for the Digital Future, 2004).

Similar to the data on interest in the Internet, these data suggest that long-term Internet users are likely to have integrated the technology in their lives across a broad set of purposes; those new to the Internet may be in the process of discovering purposes for use. Yet, both new and experienced users express similar levels of confidence that they could find health or medical information on the Internet if they needed to (Fallows, 2005; USC Annenberg School Center for the Digital Future, 2004). Although these findings suggest a strong sense of self-efficacy across user groups and perceived value of available information, they do not address different segments' understanding of and capacities to apply information.

As evidenced by the number of published studies in the peer-reviewed literature, there is a great deal of interest in who is using the Internet to search for health information and for what purposes. The Pew Internet & American Life Project has conducted extensive survey research on the public's online habits and behaviors, including search behaviors and health information-seeking (for examples, see Fallows, 2005; Fox, 2005b). The Pew Project finds that search engines are the overwhelming favorite method to find information on the Internet; 84 percent of Internet users chose search engines to locate the information they seek (Fallows, 2005).

Table 2 summarizes selected peer-reviewed research studies from the journal literature on Internet health information-seeking. The studies typically were designed to identify relevant factors of use by different audience or user segments. These studies have some utility as guides to the attitudes and interests of different audiences and users, although in most cases the findings are descriptive rather than analytical or explanatory. In general, these studies are most useful to describe how often different groups search for different types of health information and the utility or value of the information for their specific needs. Although the location from which people access the Internet was of interest in the present study, only two research studies included information on this variable (Borzekowski and Rickert, 2000; Smith-Barbaro, Licciardone, Clarke, et al., 2001).

Indicators suggest that many segments of the population are ready to think about new uses of digital technologies for health. Connecting for Health, a public-private collaborative to promote the use of health information technologies, conducted

Table 2. Selected Peer-reviewed Research Studies on Internet Use, Searching Behaviors, and Users' Attitudes and Interests

Study	Population Group	Sample Size	Descriptive Variables
Baker, Wagner, Singer, et al., 2003	Adults	4,764 self-reported Internet users	Frequency; E-mail with physician; Impact on health decisions and utilization; Online purchasing
Borzekowski and Rickert, 2000	Urban adolescent girls	176 — 86 from private high school — 90 from low-income clinic	Frequency; Topics searched for; Value; Comfort
Borzekowski and Rickert, 2001	Suburban high school students	412 socioeconomically and ethnically diverse	Frequency; Topics searched for; Value
Bull, McFarlane, and King, 2001	Internet users	4,601 who completed online survey of sexual risk behavior	Topics of interest; Functions of interest
Diaz, Griffen, Ng, et al., 2002	Primary care patients	1,000 randomly selected patients	Demographics; Topics; Quality; Consult with physician
Dutta-Bergman, 2003	Nationally representative sample	2,636 respondents to Porter Novelli HealthStyles survey	Demographics; Trusted sources of information
Feil, Glasgow, Boles, et al., 2000	Primary care patients with type 2 diabetes	160	Willingness to enroll in Internet-based diabetes self-management
Houston and Allison, 2002	Internet users who go online for health information	521 (Pew sample)	Demographics; Health status; Functions of interest; Infomediaries; Consult with physician
Kalichman, Benotsch, Weinhardt, et al., 2002	People living with HIV/AIDS	259 men and women recruited from infectious disease clinics and community-based AIDS services	Demographics; Knowledge; Self-efficacy
Kalichman, Benotsch, Weinhardt, et al., 2003	HIV-positive persons	147	Knowledge; Coping; Social support
Monnier, Laken, and Carter, 2002	Patients with cancer and caregivers	319 in waiting rooms of medical university cancer center	Demographics; Interest in topics; Interest in locus of use; Intent to use

Table 2. Selected Peer-reviewed Research Studies on Internet Use, Searching Behaviors, and Users' Attitudes and Interests (continued)

Study	Population Group	Sample Size	Descriptive Variables
Morrell, Mayhorn, and Bennett, 2000	Adults age 40 and older	550 adults in Michigan	Frequency; Topics of interest; Reasons they do not use
Pandey, Hart, and Tiwary, 2003	Adult women	1,016 women in New Jersey	Reasons to use
Peterson and Fretz, 2003	Patients with lung cancer	139 patients in university hospital cancer clinic	Demographics; Source of information comparison; Quality
Rideout, 2001	Generation Xers	1,209 young people age 15 to 24	Frequency; Activities; Influence; Behavior
Safran, 2003	Parents	300 Medicaid parents with infants in intensive care	Frequency; Barriers
Sciamanna, Clark, Houston, et al., 2002	Primary care patients	300 patients from community-based primary care practices — 109 without Internet access — 191 with Internet access	Demographics; Interest in topics; Experience with different functions
Semere, Karamanoukian, Levitt, et al., 2003	Parents	150 primarily female parents of surgery outpatients	Demographics; Frequency; Assessment of information; Impact of information
Smith-Barbaro et al., 2001	Family medicine patients	824 patients in university-based family practice clinics	Demographics

research on public opinions and attitudes about personal health records. The researchers found that although two-thirds of the public had thought very little about accessing their personal health information on the Internet, about half thought that they would like to try it. The study found that, in general, "people often do not consider electronic solutions to their personal health information management needs" (Connecting for Health, 2004, p. 47), but a large number of persons under age 65 are ready at least to consider the idea. One study in Queens, New York, found that a low-income, ethnically diverse patient population reacted very favorably to the use of "smart cards" for basic personal health records (Versel, 2004). Surveys find that e-mail for clinician-patient communication could be a popular use of the Internet, if clinicians were more willing to use it. A *Wall Street Journal*/Harris Poll

finds that although only 8 percent of adults report using e-mail with their physicians, 81 percent either strongly favor or somewhat favor doing so (The Wall Street Journal Online, 2005).

USER CHARACTERISTICS THAT INFLUENCE E-HEALTH TOOL USE

Public health interventions typically rely on broad demographic categories to identify who is affected by an issue, risk factor, or disease. Those most affected become the targets for an intervention. These demographic categories—including race, ethnicity, gender, age, income and education levels, and disability status, among others—are the basis for much of the current debate on the nature and extent of health disparities (HHS 2000, 2005a).

One of the original purposes of the present study—a purpose that could not be wholly fulfilled because of a lack of existing research and publicly available data—was to identify and analyze factors in addition to demographics that affect the adoption of e-health tools by those population segments most affected by health disparities. As noted throughout the report, studies suggest that populations that experience health disparities are also likely to experience disparities in technology access and use. Beyond these broad observations, however, little information addresses factors related to users' motivation, engagement, and understanding of e-health tools and their relevance to strategies to promote greater use. The IOM Committee on Communication for Behavior Change in the 21st Century found that "data that provide

a much deeper and more sophisticated understanding of how specific beliefs and behaviors and health status covary across the U.S. population and of how health behavior is shaped by sociocultural processes are not available. . . ." (IOM, 2002, p. 15).

Demographic characteristics or functional skills, such as low literacy, novice computer skills, and limited English proficiency, are the main factors that have been used to characterize user groups to date. Gender, education, income, and age are strong determinants of interest and behavior in health information-seeking across media, according to a review of prevention communication and media use (Lieberman, Benet, Lloyd-Kolkin, et al., 2004). Regardless of ethnicity, well-educated, affluent women under age 65 are the most active health information consumers.

Studies suggest that race and ethnicity have some association with communication processes, perhaps because of the ways that race can act as a marker or proxy for cultural factors. The literature review conducted for this study (see Chapter 3) found that few studies explicitly assessed the significance of race, ethnicity, or culture on participants' interaction with and response to technologies. A few studies did recruit participants on the basis of racial and ethnic characteristics, but they did not explore the significance of cultural influences.

Race and ethnicity are highly significant variables for health status, if only because of the impact of discrimination on health disparities. However, there is often more variation within traditional demographic

categories than between them. Moreover, the IOM Committee on Communication for Behavior Change in the 21st Century cautions that the use of overly broad or rigid demographic characteristics can actually exacerbate inequities by reinforcing inaccurate assumptions and stereotypes. This Committee calls for a focus on "more meaningful ways of describing heterogeneity," focused on cultural processes, life experience, sociocultural environment, economic contexts, community resources, and beliefs (IOM, 2002).

From a communication perspective, people attribute meaning and make sense of the messages, interactions, situations, and media around them; and they interact with and shape both the tools and the environments in which they live. Interactive media, including e-health tools, make these processes more obvious because they provide new opportunities to act as engaged users instead of passive receivers of information, "link(ing), think(ing) and interact(ing)" with information and other users (Cole, 2004). Individuals become involved in shaping an environment of highly personalized and private engagement with the Internet, Web sites, and interactive components.

Some researchers conceptualize the Internet as a "hybrid" medium with features of mass and interpersonal communication (Cassell, Jackson, and Cheuvront, 1998). Some of the many communication factors relevant to the analysis of e-health tools are patterns of media or technology use, values, beliefs, intentions, expectations, preferences,

perspectives, capacities, and access to information and technology (Neuhauser and Kreps, 2003). The characteristics of technology are important in terms of its fit with, value for, and usability by different user groups (Badre, 2002; Nielsen, 1999; Norman, 2002).

The lack of research on psychosocial variables other than health information-seeking as well as the lack of multivariate analyses of demographic and communication factors are major gaps in the literature (Lieberman et al., 2004). A few studies have examined the motivations or level of interest of potential or actual users of e-health tools—typically health information Web sites, online communities, or provider-patient e-mails. It is easier to know who, in demographic terms, is or is not using computers and the Internet than it is to know how individuals think about what they do online and how the interaction reinforces or changes their attitudes, beliefs, values, and preferences.

Despite the paucity of research, however, some things are known about factors that influence health communication processes and audiences' interactions with media. The most influential characteristics that have some evidence of their relevance are discussed briefly below.

Language Spoken

The relevance of language spoken to the use of e-health tools cannot be overstated. If individuals or groups use one language and the tool is based on a different language, users are very unlikely to make

sense of the tool and the content. English-language materials dominate the Internet, which limits the utility of the content for those who read little or no English (The Children's Partnership, 2000).

Approximately 19 percent of the population speaks a language other than English, according to 2004 Census Bureau data (U.S. Census Bureau, 2004). The majority of persons in this category are Spanish speakers (62 percent); Chinese is a distant second. Data from the Census and the U.S. Department of Education suggest that the majority of persons who speak a language other than English at home consider themselves able to function "very well" in English (Greenberg et al., 2001; U.S. Census Bureau, 2000). Overall, the Census Bureau reports that 92 percent of the population over the age of 5 years report that they do not have difficulty functioning in English (U.S. Census Bureau, 2000). Census data indicate that approximately 4 percent of the population is "linguistically isolated" (U.S. Census Bureau, 2000). Despite this picture of English-language functioning, these data do not speak to issues of language preferences of different groups, the significance of language as an element of culture, or the role of language in perceptions of health and illness.

"Linguistic appropriateness" may seem straightforward, but it is not. Fulfilling the proviso that communication should be in the primary language of the target audience is not simple for large and diverse population groups, given the number of versions of a given language. For example, Spanish speakers present an interesting example of the complexities of linguistic

appropriateness. This population segment is both culturally and linguistically diverse, coming primarily from multiple countries in Latin America and the Caribbean and with distinct cultural origins related primarily to Africa, indigenous America, and Europe. Despite the cultural relevance of slang, dialect, and vocabulary, there is often an imperative to identify a "common" Spanish that will function cross-culturally (Schroeder, Trowbridge, and Price, 2002). One of the few general studies of factors relevant for Hispanic groups' use of the Internet found that Hispanics encounter many barriers when trying to locate Spanish-language health information online (Schroeder et al., 2002).

At the same time, market research reports on Hispanics' Internet use indicate that they are going online faster than any other segment and are finding content of interest in the categories of communication (e.g., instant messages), entertainment (particularly music), and product information (*Hispanic Market Weekly,* 2006). When they perceive the relevance of the content, Hispanics are willing to go online to "compare prices, see features, learn about benefits, and then decide on a brand or purchase," according to the publisher of *AOL Latino* (cited in *Hispanic Market Weekly,* 2006).

Small-scale studies of the health information needs and preferences of Asian Americans, Native Hawaiians, Pacific Islanders, and Native Americans suggest that lack of content in the first languages of ethnic groups and inexperience with Internet resources are major barriers to greater use (Hsu, 2003a, 2003b). However,

these factors have yet to be analyzed in terms of their contribution to overall lower rates of Internet usage and demand for e-health tools. For example, in a national survey of unpaid caregivers, only 5 percent reported that "finding non-English educational materials" was an unmet need (National Alliance for Caregiving and AARP, 2004).

In the scan of e-health tools conducted for this report (see Appendix 1), language and literacy emerged as two critical considerations in the design of successful tools. Even if developers did not report using any other methods to account for audience variations, they did mention creating understandable materials as design and content priorities. Designing for a stated reading grade level seemed to be the most popular strategy to make content more understandable. Providing content in Spanish was the most popular alternative to English.

Both these strategies have their own problems and raise a number of issues concerning the utility and comprehensibility of content. Even when content developers attempt translation, the quality of translations and the readability of materials can present problems. For example, translations can be of poor quality and reproduce problems, such as jargon and unfamiliar terms, that were features of the original text. Texts that meet a stated reading grade level can still make it difficult for users to understand the core meaning. Applying a health literacy approach that engages intended users in the development of the content from the beginning and focuses on assessing

usability and understanding seems the most promising mechanism to address issues of language and literacy.

Socioeconomic Position

IOM proposes that the most important forms of diversity to pay attention to in health communication are those associated with "substantial disparities in health status and outcomes" that also represent differences in "health behavior and its antecedents" (IOM, 2002, p. 7). Individually and collectively, the components of socioeconomic position—including income, employment status, wealth, education, housing, and neighborhood environment—influence health, health behavior, and factors involved in health communication. IOM's *Promoting Health* report discusses the relationships among these factors (2000). Communication theory from the 1970s proposed the existence of a "knowledge gap," which represents the divide between higher socioeconomic persons who pay closer attention to and have greater access to information than lower socioeconomic persons (Tichenor, Donohue, and Olien, 1970). In the e-health arena, socioeconomic factors are major determinants of the elements of meaningful access, as discussed above.

Preliminary analysis of national data from the Health Information National Trends Survey, conducted by the National Cancer Institute (NCI), suggests that income and education levels, as well as gender and age, strongly influence the amount of attention people pay to health

topics (Hesse, 2003). A study by Tu and Hargraves indicates that level of education is the most important predictor of health information-seeking; 55 percent of people with postgraduate education said they sought health information, compared with only 25 percent of those without a high school diploma (2003). Education level is also strongly associated with literacy skills, which are a component of health literacy. The relationship between education and literacy likely goes both ways: those who stay in school longer likely have stronger literacy skills, and those with stronger skills likely stay in school longer. This relationship indicates that there is much to learn about how both education and literacy affect people's access to, interest in, and engagement with health information and the pathways for development of communication capacities.

Disabilities

An estimated 54 million Americans—20 percent of the population—have disabilities (HHS, 2000). Disability, by definition, involves the interaction of impairments and environmental barriers; removing or reducing a barrier can reduce a disability. The types of impairments can include visual, hearing, mobility, cognitive, and learning disabilities. Each type of impairment corresponds to a set of accommodations needed to reach a particular audience segment with effective e-health resources. Disabilities affect people of all ages, but the proportion of the population affected increases with age; therefore, because the U.S. population is aging, the proportion of Americans with

disabilities is growing (HHS, 2005b). There are many crossovers between the topics discussed in this section and those on the characteristics and communication needs of older adults and family caregivers, described below. Although people with disabilities are not necessarily in poor health, they are at increased risk of secondary conditions and may have less access to health services and medical care. Health promotion to improve functioning and reduce the incidence of secondary conditions has been shown to be effective (HHS, 2000).

A report by the Pew Internet & American Life Project includes a "special analysis" on Americans with disabilities (Lenhart et al., 2003). The research shows that 38 percent of Americans with disabilities use the Internet, compared to 58 percent of the entire population. Users with disabilities are more likely than the general population to have access only at home (58 percent versus 44 percent, respectively) as well as more likely to look for medical information online (75 percent versus 59 percent, respectively). The Pew research also yielded insights into the reasons persons with disabilities give for not going online—some of which, such as misconceptions about the Internet, are amenable to solution (Lenhart et al., 2003).

For people with disabilities, digital divide issues apply not only to Internet access but also to a broad set of assistive and adaptive technologies that increase accessibility of all kinds. Some of these technologies, which have been likened to "electronic curb cuts," enable access to the Internet and other digital resources for people with disabilities. Physical barriers to Internet use—or,

alternatively, accommodations—can exist at many points, including the public access computing site, the computer terminal, the Web site, the Internet service provider, the browser, and the Web-based platform. Designing for persons with impairments was rare in the 40 e-health tools reviewed for this report (see Appendix 1). Only one makes specific accommodations for people with hearing or visual impairments.

Once physical access to computers and the Internet is achieved, the next set of issues relates to the design, content, and delivery of digital information resources. Paradoxically, although the Internet can reduce the isolation that can come with disability, it also presents its own barriers that must be overcome before it can be useful. The specific barrier, and thus the solution, varies with the impairment, and a detailed review of the often quite technical ways to achieve accessible Web design is beyond the scope of this brief overview. The creator of cascading style sheets, one such mechanism, points out that Web-based information involves the interaction of "content and presentation," and these have to be addressed separately in order to successfully communicate with people with visual and hearing disabilities (Bartlett, 2002).

The types of accommodations in content and presentation for people with disabilities can be beneficial to other e-health audience segments as well, such as seniors and people with limited literacy or English proficiency. The accommodations include multimedia presentation, breaking text into small chunks, and allowing users to control font size and other visual attributes.

Techniques such as these, together with general principles of user-centered design and usability testing (described below), can result in e-health resources that are beneficial to all people, including those with disabilities.

The problem of inadequate research to guide design and content decisions figures in this context as it does elsewhere. Apart from the few references noted above, the present study found no empirical research on health communication issues for people with disabilities. This finding was confirmed by staff members of the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, who conducted an unsuccessful literature search on health communication and disability in preparation for a health promotion campaign for women with disabilities (J. Thierry, personal communication, October 2004).

Developers can draw on a combination of laws, guidelines, and evaluation tools in achieving and measuring accessibility. Federal law on accessibility is in Section 508 of the 1973 Rehabilitation Act (revised based on the Americans With Disabilities Act), which requires that Federal agencies' electronic and information technology be accessible to people with disabilities. An article in the *Journal of Medical Internet Research* reported on research that evaluated 108 Web sites for consumer health information according to disability accessibility guidelines; the researchers found that Government and educational sites are the most accessible, presumably at least partly

because of Section 508 requirements for Government sites (*www.section508.gov/*). No site met all the criteria, however (Zeng and Parmento, 2004). Although the requirements only apply to Federal sites, some private Web developers choose to comply as well. (See Chiang and Starren, 2004, for another published evaluation of Web access for people with disabilities).

The World Wide Web Consortium (W3C) Web Accessibility Initiative has developed its own Web Content Accessibility Guidelines (WCAG) for determining Web page accessibility (*www.w3.org/WAI/*). The Web site of the International Center for Disability Resources on the Internet leads to a long chain of useful resources (*www.icdri.org/prodserv.htm*). The same is true of "Bobby," a Windows-based tool that provides a free service to analyze Web pages for their accessibility to people with disabilities, to identify and repair barriers to accessibility, and to facilitate compliance with accessibility guidelines such as Section 508 and W3C's WCAG (*http://webxact.watchfire.com/*). One expert reports that current Web accessibility guidelines do not address cognitive disabilities very well, as most of the focus to date has been on visual and sensory disabilities (R. Appleyard, personal communication, October 2004, citing Wehmeyer, 1998, 1999).

Age, Developmental, and Role Issues

As noted above, age is one of the most important factors affecting health status, information-seeking, media use, and Internet behaviors. Yet little attention has

been paid to life course, roles (apart from parenting), and experiential variables that are often associated with age. Each phase of life has its own developmental perspective, obstacles and facilitating factors, and unique experiences that influence interests and capacities related to health communication. For example, unpaid caregiving by adults for adults is emerging as a critical policy issue as well as an experiential factor for millions of Americans. A survey by the National Alliance for Caregiving and AARP estimates that approximately 44 million adults provide unpaid care to other adults (National Alliance for Caregiving and AARP, 2004). The survey finds that "the typical caregiver is a 46-year-old woman who has at least some college experience and provides more than 20 hours of care each week to her mother." Approximately one-third of caregivers rely on the Internet for information to help them cope with their caregiving (National Alliance for Caregiving and AARP, 2004, p. 68).

Internet use is inversely associated with age. Only 22 percent of people older than age 65 have been online (Fox, 2004), compared with 96 percent of children and adolescents age 8 to 18 (Rideout, Roberts, and Foehr, 2005). The higher percentage of young people online is to a great extent due to school-based access, whereas home access remains a concern for the large segment of low-income children. Home-based access is also important for older adults, who are more likely to be out of the workforce or homebound. Partly because of young people's greater exposure to technology, training, and technical assistance opportunities, they show greater comfort and facility with technology than older

adults. (Indeed, some programs involve them as trainers, as seen in Chapter 5.) Older adults are more likely than persons in other age groups to have physical or cognitive impairments that further limit their ability to use computers and navigate the Internet (Morrell, Dailey, Feldman, et al., 2003; SPRY Foundation, n.d.).

However, both groups have shown considerable interest in health topics. Older adults use their Web access for health purposes more intensively than other age groups (Fox, 2004); and 68 percent of 15- to 24-year-olds and 50 percent of all 8- to 18-year-olds who have been online have used the Internet to get health information (Kaiser Family Foundation, 2001; Rideout et al., 2005).

One study is suggestive about the relationships among age, experience with both health and technology, and use of e-health tools. It examined participation and nonparticipation rates by primary care patients with type 2 diabetes in an Internet-based diabetes self-management support program (Feil, Glasgow, Boles, et al., 2000). The researchers found no significant differences in gender, insulin use, computer familiarity, or computer ownership. The significant differences between participants and nonparticipants were related to age and years since diagnosis; younger patients with more recent diagnoses were more likely to participate.

A relatively recent development of special relevance for older adults, including the significant percentage who are caregivers, is the growing use of disease management tools by healthcare organizations. Older

adults have the largest incidence of costly chronic illnesses, and major institutions such as the Centers for Medicare & Medicaid Services (CMS) and the U.S. Department of Veterans Affairs (VA) are investing in the development of e-health tools to help patients manage their diseases. These programs provide training and sometimes the necessary equipment. If this trend continues, at least a small segment of older adults may be induced to become users of electronic communication and information for personal health management. In addition, the Web portal being developed for Medicare beneficiaries introduces them to an e-health tool that contains content of direct relevance.

Although the specifics vary considerably, both older and young age groups have style preferences, technology use characteristics, and health content interests that are often not served by standard e-health tool content, design, and architecture and that are best accommodated through targeted tools. The top priorities for meeting the needs of older and younger users include simplicity of design and content and the use of multimedia presentations. One example of applying good design practices and research-based knowledge of intended users is the Web site for older adults sponsored by the National Institutes of Health (*www.nihseniorhealth.gov*). The site is designed to accommodate limited literacy levels, cognitive and physical impairments, and different modes of learning (e.g., textual, visual, auditory). The Web site's approach closely matches the general principles of good Web design for all users promulgated by the Federal Government (see *www.usability.gov* and

www.firstgov.gov/webcontent). Many
e-health tools designed for young people
have behavior change and prevention
purposes; here the challenge is to make
them interesting and attractive.

Interest in Health Information

Health information-seeking attitudes
and behaviors, as well as attitudes and
behaviors toward health care and healthcare
providers, have been identified as a useful
basis for segmentation with respect to
e-health communication. Researchers and
expert observers classify people in terms of
their degree of independence and initiative
in relation to health care and health
information-seeking. For example, research
by the communication firm Porter Novelli
found that the public can be segmented
into five health information types, based
on two broad sets of characteristics—
degree of reliance on physicians for health
information and level of activity in seeking
out such information (cited in Lieberman
et al., 2004).

- **The Uninvolved** (14 percent) are likely
  to describe their health as good or fair;
  value health less than others do; expend
  less energy on prevention; and exhibit
  low interest in health information.

- **Doctor-Dependent Passives** (20 percent)
  describe their health as excellent or very
  good; hold lower values for health and
  prevention; and express low interest in
  health information.

- **Moderates** (28 percent) are generally
  healthy adults; value good health and
  actively try to prevent disease; and value

health information, but do not enjoy
searching for it and may lack skills
to do so.

- **Doctor-Dependent Actives** (20 percent)
  value health and prevention, but
  experience more health problems; and
  actively seek health information and
  are capable of finding it, but may have
  difficulty interpreting it.

- **Independent Actives** (19 percent) are in
  very good health; highly value health and
  prevention; place the highest importance
  on health information; and are very
  skilled at finding and understanding
  health information.

Long-time online health activist and
analyst Dr. Tom Ferguson proposes a
new vocabulary to capture the shift in
individuals' orientation to information and
their health. Instead of "consumers" or
"patients," he sometimes speaks of "medical
end users," "e-patients," and "prosumers,"
the last term coined by Alvin Toffler in
The Third Wave to capture the blurring of
the distinction between service providers
and recipients (Ferguson, n.d.). Similar
to the Porter Novelli categories, Ferguson
divides patients and consumers into three
groups—passive patients, concerned
consumers, and health-active prosumers—
and he predicts an increasing shift into the
third group. In addition to information, he
stresses the importance of communication
among consumers, such as in online and
face-to-face support groups.

Dr. Judith Hibbard has developed a
multifaceted typology to assess levels
of "health activation" in patients and

consumers (Hibbard, 2003).[2] Her work primarily concerns health behaviors, but it is highly relevant to health information-seeking and use. Hibbard's "activation measure" assesses patients along two axes, one listing actions the individual can take related to personal health and the other listing the capacities to be assessed with respect to those actions (Table 3).

Hibbard states that consumers with higher activation are more likely to take such actions as read about possible complications when taking a new medication, seek out health information, visit a health Web site, and know about treatment guidelines for their condition. The relevance of her work for the present report is summarized in two questions she poses:

- What kinds of strategies will be most effective in increasing activation?

- How can we take advantage of knowing a patient's activation level to tailor an intervention?

Attitudes About Privacy and the Protection of Personal Health Information

Since the initial framing of this project and drafting of the report, the issues of protecting personal privacy and ensuring the confidentiality of personal health information have moved to the top of the agenda in any discussion of consumer e-health tools, particularly personal health records. Numerous documents assert that there must be strong privacy protections for e-health tools that collect and store personal health information; the need for

2 This discussion is based on several of Dr. Hibbard's articles and on her slides, "Measuring and Improving Patient Activation," for a presentation to a September 2003 conference of the Center for Information Therapy. *www.informationtherapy.org/conf_mat03/final_pres/Hibbard.pdf*.

Table 3. Domains for Measuring Activation Measure

	. . . self-manage	. . . collaborate with provider	. . . maintain function/prevent declines	. . . access appropriate and high-quality care
Has the knowledge to:				
Has the skills to:				
Can access emotional supports to:				
Believes patient is important in:				

Source: Judith Hibbard, Dr.P.H., University of Oregon. Slides presented at Center for Information Therapy conference, September 2003.

strong protections has been particularly noted in relation to personal health records (Markle Foundation, 2005; NCVHS, 2005a). Several national surveys have been conducted to gauge public understanding of privacy issues and the public's expectations about privacy protections in an e-health environment (California HealthCare Foundation, 2005; Markle Foundation, 2005; Westin, 2005). The findings are consistent that a majority expect strong privacy protections, whether through policies, laws, or technologies.

The findings of two surveys suggest, however, that as in most other areas, segments of the public can be distinguished on the basis of their attitudes toward privacy, and likely by their privacy-protecting behaviors as well (California HealthCare Foundation, 2005; Westin, 2005). As with other factors discussed in this chapter, attitudes about health information privacy and e-health tools have not been well studied. It is possible to infer from user behavior in online communities, however, that participants do not perceive all disclosures of personal information as equal. Participants often post highly personal and identifiable information in online chats and blogs; yet a disclosure of the same or similar information as a result of a security breach of a digital record system would likely be treated as a privacy violation.

In numerous hearings on personal health records, the National Committee on Vital and Health Statistics consistently heard testimony that the key factor for consumers is their ability to control their own information and records and protect their privacy (NCVHS, 2005a, 2005b). In

light of the preceding discussion on the diversity in information-seeking behaviors and activation toward health, the need for control and sensitivity to disclosures also should be treated as having a range of values rather than dichotomous values of either total or no control and sensitivity to disclosure of personal information.

DESIGNING FOR DIVERSE USER GROUPS

Given the number of factors that must be considered when designing tools to meet the needs of diverse users, it is clear that a focused effort by developers is required. Engaging persons with low income or education, different ethnic groups, and adults with limited literacy skills in health communication requires sophisticated audience segmentation techniques that involve intended users of the information in interactive roles (Freimuth and Mettger, 1990). Targeting (audience segmentation) and tailoring on communication factors are considered promising strategies for user-centric design in the electronic environment (IOM, 2002). Both are employed to engage users by personalizing and individualizing information based on demographic, behavioral, motivational, psychosocial, or physical characteristics (Brug, Oenema, and Campbell, 2003).

Targeting or audience segmentation is selecting groups of users based on common characteristics related to behavior, health status, or some other common factor. The process of targeting generally happens in the following sequence. First, a target audience or market is identified, related to a healthcare or public health need or a business opportunity. Then, the audience

is analyzed, and if necessary, segmented, to optimize service and impact. In some cases, specialized products and services are developed for existing audience segments or new target audiences. Some tools integrate tailoring capabilities that make it possible to accommodate individual differences. This sometimes involves "cultural tailoring," or tailoring to enhance the impact for individuals in targeted audience groups (IOM, 2002).

Tailoring is designed to simulate personal counseling in that the individual is surveyed and the responses are used to generate individualized information and feedback (Brug et al., 2003; IOM 2002).[3] Tailored information has been shown to be more satisfying, read more deeply, seen as more personally relevant, and more often discussed with others (Brug et al., 2003). "First-generation" tailoring involves using a computer program to generate the individualized feedback that is presented to the user in a print-based format, such as a letter or newsletter. "Second-generation" tailoring takes advantage of the computer's ability to immediately deliver tailored information and eliminates the lag time incurred while waiting for printed, tailored information to be presented (Oenema, Brug, and Lechner, et al., 2001).

Dr. Victor Strecher and Dr. Kevin Wildenhaus at the University of Michigan are leading practitioners of computer-based tailoring in health communication. They prefer tailoring over targeting to enhance the effectiveness of health communication messages. When asked

to identify the intended user groups or populations served by the e-tools his lab develops, Dr. Strecher stated, "Targeted messages miss the important variation in behavioral predictors that are often found within demographic or even psychographic groups. Tailoring identifies these predictors at an individual level and addresses them." He further stated, "Our most recent research suggests that deeply tailored materials seem to help the people who need them the most—those with low perceived capabilities in solving problems on their own. Tailoring may particularly help these individuals by providing a very individualized plan and by conveying information in a more vivid manner" (V. Strecher, personal communication, March 16, 2006). The National Cancer Institute (NCI) has funded Dr. Strecher's lab to work on identifying the "active ingredients" that make computer-based tailoring successful.

Enhancing the usability of Web sites is another strategy to make e-health tools more fully accessible to all users (Koyani, Bailey, and Nall, 2003). In the Government context, the HHS Web team and NCI have played a leading role in developing and implementing a usability approach to improve the navigation of Web sites (*http://usability.gov*). Usability testing can be used on its own or as part of a broader approach known as user-centered design.

User-centered design is an iterative process that assesses tools throughout the design life cycle in terms of users' preferences and performance. The process includes task and user analysis and participatory methods, such as focus groups and surveys, to determine the interests and capacities of

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3 For a book-length treatment on computer-based tailoring, see Kreuter, Farrell, Olevitch, et al., 2000.

prospective users. Later, usability testing determines how well users are able to use a given tool, with the goal of uncovering problems that can be fixed prior to launch. The Think Aloud protocol is a method in which users describe their thought processes as they make their way through a Web site. Other methods include contextual inquiry (observation and testing), interviews, journals, various forms of inspection, and performance measurement.

The major criteria are users' success in finding information, including accuracy and speed; related criteria are likability, learning, and retention. For example, in one small study, adults with low literacy were able to learn Web navigation skills easily and use interactive features such as active graphics and pull-down menus when the instructions were simple, direct, and noticeable (Zarcadoolas et al., 2002).

In an effort to identify the types of user-centric strategies currently in use by e-health developers in the field, project staff interviewed 54 developers and other experts about 40 e-health tools designed wholly or partly for diverse users (see Appendix 1). Each of the tools proved to be distinctive in the way it combines functions and features to serve intended users. The analysis of this set of tools suggests the number of user variables that can be considered and the many ways developers think about enhancing relevance and engagement. These developers report that they often consider literacy levels relevant to the use of e-health tools, although the literature review in the next chapter indicates that few studies have systematically included persons

with limited literacy skills, designed tools as health literacy interventions, or assessed health literacy as part of the evaluation of the tool.

The scan of 40 e-health tools indicates that developers employ a variety of strategies to enhance the connection between the tools and their intended users. The main strategy appears to be one of targeting or segmentation. The findings align with the observations made in the IOM report, *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations,* about the adaptation of health communication for diverse audiences (2002):

- Some tools are developed for narrowly defined audiences (e.g., people over age 65 with chronic obstructive pulmonary disease; binge-drinking college students). Some developers have an array of such specialized tools or modules.

- Some tools are developed for a broad cross-section of users, but adapted to serve different audience segments (e.g., a Spanish-language version, a module for pregnant women, a chat room for caregivers). The broad cross-section may exist because the tool is available to all comers (e.g., through a public Internet site) or because it is distributed to a restricted but diverse constituency (e.g., employees of a distributor, health plan enrollees).

- Some tools are developed for a broad (and presumably heterogeneous) user group in a way that focuses on what all users have in common.

Often, tools are designed for large population segments based on public health priorities, such as kids with diabetes or adult smokers who are trying to quit. Several developers mentioned the economic impracticality of designing highly segmented or individually tailored tools. Many tools, such as public Web sites, serve anyone who finds the site on the Internet. Others may serve anyone in a more restricted but still heterogeneous group, such as members of a particular health plan or employees of a large organization. Targeting is often based on one or two dominant factors, such as shared health issues, gender, or age. Health condition, risk behavior, and age were the most popular factors for identifying intended users of e-health tools. Some developers stated that the most important characteristic in targeting was the shared health issue, such as people with cancer and their caregivers, rather than demographic factors. The implication is that shared health experience is the basis for coming together via technology. For the majority of the 40 tools, medical conditions (e.g., diabetes) or health-risk behaviors (e.g., smoking) define the audience.

In all, 19 of the 40 tools in the scan were described as having one or more special features for one or more diverse groups. Most consider multiple audience characteristics. The bases for audience segmentation among the tools (listed in order of frequency) are age, language, race/ethnicity, gender, income, geographic location, and disability or sensory impairment. The segments targeted by these tools include:

- Hispanics/Latinos
- Other non-English speakers
- African Americans
- Recent immigrants (e.g., Vietnamese, Caribbean)
- Women
- Teenagers
- Young children
- Elders
- People with low income
- Rural dwellers
- Inner-city dwellers

Added to these variations, several e-health tools have versions for intermediaries or adjunct users such as childcare providers, teachers, parents, school friends, and public health workers. The large group of healthcare tools (i.e., tools made available by healthcare providers or organizations for use by their consumers/patients) are also used by staff members of the healthcare organization, such as nurses, administrative staff, and personal physicians, and these are distinct user groups from the perspective of tool development and evaluation.

The interviews offer examples of developers who adapted a single basic program with multiple subprograms based on factors such as gender, age, or severity of disease. One company has 22 versions of its basic

program. This finding suggests that the often-discussed potential of technology to create customized versions of generic interventions is starting to be realized in the marketplace through a variety of approaches.

SUMMARY

This chapter identifies several concepts, factors, and strategies that can be used to design e-health tools for diverse users. The concepts of health literacy and meaningful access highlight the importance of ensuring physical access to information and technology and designing useful, understandable content. The IOM has already called for greater attention to communication factors in the design of health information, messages, and e-health tools. This chapter elaborates on many of the critical factors for user-centric design. If the vision of e-health tools for all is to be realized, these factors, along with others that have yet to be fully articulated, will require further research and integration into tool design and development. A scan of the current field of e-health tools indicates that developers are beginning to address issues of diversity, but do not yet have strategies and approaches that go much beyond traditional public health targeting based on demographic characteristics. Developers will need to engage consumers more fully in the research and design process and probe those factors that shape attitudes, beliefs, values, expectations, and experiences in relation to health and technology.