CHAPTER 3. ASSESSING THE EVIDENCE FOR e-HEALTH TOOLS FOR DIVERSE USERS

INTRODUCTION

This chapter summarizes and analyzes recent research literature on e-health tools to clarify what about e-health tools for diverse users is working well and where more and different research is needed. Critics argue that over-reliance on e-health tools can increase disparities rather than reduce or eliminate them; therefore, it is vital to identify when e-health tools can help to narrow gaps. The Institute of Medicine (IOM) report, *Speaking of Health*, proposes that several factors are relevant for assessing e-health for diverse populations: access, availability, appropriateness, acceptability, and applicability of content (2002). This chapter uses these concepts, referred to as the "Five A's," to organize key research findings and discuss their implications for tool design, use, dissemination, and impact. The review suggests that design and dissemination factors are closely connected to and likely to affect the impact of the tools according to a variety of outcome measures.

Previous reviews also have looked at the evidence base for e-health but have not focused as closely on design, use, and dissemination issues as the present review (Eng, 2001; IOM, 2002; Neuhauser and Kreps, 2003; HHS, 1999). These other reviews point not only to the great promise of e-health tools, but also to the need to moderate enthusiasm by recognizing factors that can limit the tools' potential.

Numerous individual examples of research-based tools usually produce the desired effects. To date, however, no systematic body of knowledge or theoretical frameworks explain what processes or contextual factors produce and mediate these effects or what the effects would be for different kinds of e-health tools used by different audiences (Neuhauser and Kreps, 2003). Given that some population groups experience a disproportionate amount of disease and overall poor health, it is critical to use the research enterprise to understand if and how e-health tools might be designed and deployed to reduce rather than exacerbate disparities and improve individual and population health.

METHODOLOGY AND RATIONALE FOR REVIEW

This review selected research studies using experimental design, as well as relevant review articles, that either were meta-analyses or summaries of experimentally based research studies. After the initial round of article selection, the inclusion criteria were made less stringent to increase the breadth of coverage in certain areas. For example, no randomized controlled trials were found for healthcare tools because they are relatively new in the e-health arena. Therefore, studies were included that surveyed user satisfaction and ease of use to provide some insight into these tools. Similarly, in the area

of online communities and health information, studies using content analysis provided important findings relative to the potential utility of these tools for different subpopulations; these were also included. Only studies published in peer-reviewed journals were considered. The intent was to identify those studies that used scientific methods and had already been reviewed by the field and found to be significant enough for publication.

Although this approach differs from the most rigorous evidence reviews, such as those conducted by the Cochran Collaboration or sponsored by the Agency for Healthcare Research and Quality, the purpose of the present review is not to differentiate research based on methodological rigor. The intent is to highlight the presence or absence of solid research on key elements affecting e-health use and dissemination. The recent Cochrane Collaboration review, "Interactive Health Communication Applications for People With Chronic Diseases," should be consulted for an example of a rigorous review of the science and conclusions about the effects of e-health tools on persons with chronic diseases (Murray, Burns, See Tai, et al., 2006).

The literature search used the overarching purpose categories to identify studies for inclusion: health information, behavior change/prevention, online communities, healthcare tools, decision support tools, disease management, and health self-management. Research studies for these categories were identified through the use of the following databases: PubMed,

Medscape, Medline, PsycINFO, CINAHL, and the Social Sciences Citation Index. The searches covered the time period from January 1999 to September 2004 to identify recent literature. The CRISP (Computer Retrieval of Information on Scientific Projects) database maintained by the National Institutes of Health and covering federally funded biomedical research projects was searched twice approximately 6 months apart in 2004 to identify new research either just being concluded or in progress; the same search terms were used as above. Review of the reference lists and suggestions from an expert panel and expert interviews also identified articles.

Critical information was extracted from each article and summarized into a matrix table. The matrix, presented in Appendix 3, contains data on the study's author, research design, sample, health topic area, locus of use, technology, tool description, study overview, measures, and outcomes. The table is subdivided by study design. The first section includes the studies using randomized controlled designs. The table then moves through quasi-experimental designs, single-group studies, and content analyses. Within each research design subsection, studies are arranged alphabetically by author. Each study has been assigned a unique identifying number to allow easy location of that study in the table. Each citation in this chapter includes a table reference number (TR#). To return to the text from the table, the chapter section in which the study is cited is indicated in brackets after the citation in the table.

Overview of e-Health Tools in Studies Reviewed

Most of the e-health tools in the studies reviewed below are multicomponent interventions designed to impact many aspects of personal health self-management, including prevention, behavior change, decisionmaking, and chronic disease management (see Chapter 1). This review found that although e-health tools have been developed for a wide variety of health topics and purposes, some topics and purposes appear to have greater representation in the research literature. Areas with the largest numbers of tools are nutrition education, weight management, tobacco cessation, and cancer and diabetes prevention and management. Although most of the tools in these studies are designed for adults, some target children and adolescents. Some tools, such as those for behavior change, are grounded in a theoretical framework. Others, such as healthcare tools, are emerging in response to market and policy demands and do not yet have much of a scientific basis to suggest that they will have their intended effect.

Each tool contains health information specific to its intended purpose. This information can be general, targeted to a specific user group, or tailored to an individual user. In addition to information, other features might include interactive games and simulations, video clips, chat rooms, message boards, e-mail to and from healthcare providers, self-assessments, decisionmaking tools, disease management tools, and links to other sites. Tools designed for a similar purpose do not always contain the same components.

Several studies in the review do address the effectiveness of specific components of the computer-based intervention (Baranowski, Baranowski, Cullen, et al., 2003, TR#39; Feil, Noel, Lichtenstein, et al., 2003, TR#10; Napolitano, Fotheringham, Tate, et al., 2003, TR#23; Neighbors, Larimer, and Lewis, 2004, TR#24; Tate, Wing, and Winett, 2001, TR#34). Tate and colleagues used two different e-mail approaches in their study (Tate, Jackvony, and Wing, 2003, TR#33). Both the control group and the intervention group received access to a weight-loss Web site and weekly e-mail reminders to submit their weight; the intervention group also received individual e-counseling from a weight-loss counselor. The researchers found that, compared to the control group without the individualized counseling, the intervention group doubled the percentage of initial body weight lost.

Neighbors and colleagues studied the unique impact of personalized normative feedback alone on drinking behavior in college students and found changes in misperceptions about drinking norms and on drinking behaviors (2004, TR#24). Studies from the D-Net (diabetes) projects indicated that participants using interventions with a support component improved in perceptions of support and actually had higher login rates than the other intervention groups and the controls (Barrera, Glasgow, McKay, et al., 2002, TR#2; Glasgow, Boles, McKay, et al., 2003, TR#13). Studies of CHESS (Comprehensive Health Enhancement Support System), an Internet-based program to help patients cope with cancer and other diseases, have found that use of the component parts of the system vary by a number of

demographic factors, including race and income (Gustafson, Hawkins, Pingree, et al., 2001, TR#15; McTavish, Pingree, Hawkins, et al., 2003, TR#88). These types of studies are an important beginning to help clarify what about e-health tools for diverse user groups is working and what is not.

The majority of the tools reported in the research studies were Internet-based interventions that could be accessed from personal computers. Some studies used CD-ROMs to deliver the intervention. Other delivery mechanisms used in these studies included a telephone-linked communications system (Delichatsios, Friedman, Glanz, et al., 2001, TR#9; Pinto, Friedman, Marcus, et al., 2002; TR#27), videophones (Ryan, Kobb, and Hilsen, 2003, TR#73), computers in freestanding kiosks in community settings (Anderson, Winett, Wojcik, et al., 2001, TR#1; Radvan, Wiggers, and Hazell, 2004, TR#70; Valdez, Banerjee, Ackerson, et al., 2002, TR#35), a fingerprint reader (Sciamanna and Clark, 2003, TR#31), and home telehealth units (Finkelstein, O'Connor, and Friedman, 2001, TR#11; Kaufman, Starren, Patel, et al., 2003, TR#63; Ryan et al., 2003, TR#73).

In their reports of findings, researchers do not often discuss their rationale for choosing a specific delivery method. The intended locus of use and the amount of graphics are current factors that appear to influence the decision. For example, Napolitano et al. (2003, TR#23) and Lenert and Cher (1999, TR#65) report that they delivered their interventions via the Internet to reach a potentially wide audience of users who could access the intervention from any location. Proudfoot, Goldberg, Mann, et al. used a CD-ROM-based program with

video vignettes, which was designed for delivery in a clinical setting (2003, TR#28). Because it is possible to convert content on compact discs (CDs) for use on the Internet and vice versa, the distinction between formats will likely become less relevant. At the present time, when graphics-heavy CDs are moved onto the Internet, there may be lengthy download times that can affect usability and satisfaction, particularly for those using older computers or slow Internet connections (Baranowski et al., 2003, TR#39). If broadband costs decline and more users opt for high-speed access, connection speed may become less of a problem, but not necessarily, given the size of the access gaps described in Chapter 2.

SYNTHESIS OF FINDINGS FROM RESEARCH STUDIES OF e-HEALTH TOOLS

Access

Issues of access underlie all studies of consumer e-health tools. This brief section focuses on the impact of disparities in access on the validity of findings reported in the literature. (See Chapter 2 for a general discussion of access issues.) The most important issue relates to the external validity of the research. Findings from this review indicate that many studies included only participants who have computers, thereby excluding those who lack computers or Internet access. A few studies recruited participants directly from Internet Web sites, making it less likely that people without regular access would be considered for the sample. The access criterion for study participation affects the generalizability of the findings for other

population groups or the population at large. Because people without computers also tend to have less education, lower incomes, and poorer health, the bias in the current literature must be recognized, and the need for ongoing and future research to include diverse populations is critical.

Access for all population groups is an issue. A few studies, particularly in the area of online communities, have provided participants with computers and expected no computer experience from their participants (Gustafson et al., 2001, TR#15; McTavish et al., 2003, TR#88). These studies are encouraging in that the researchers found that user technology support was not difficult and, ultimately, users were able to use the technology to give and receive support in the online communities. Providing computers for public use can be another avenue for increasing access; however, Radvan et al. found that one reason people did not use a community-placed computer-kiosk for health information was that they did not feel comfortable using the kiosk in public (2004, TR#70).

In a study of older adults, Kaufman et al. found that use of the computer and mouse was very difficult for elderly participants with diabetes who had limited computer experience (2003, TR#63). For this age group, more attention may need to be paid to choosing technology that is suitable to the users' needs. For example, Ryan et al. in the Community Care Coordination Service of the U.S. Department of Veterans Affairs (VA) used a unique approach in which they matched technology to users based on their clinical need and ability,

rather than on the availability of a specific kind of technology (2003, TR#73). Their matching process was based on the patient's education, vision, manual dexterity, willingness to use technology, and adherence to medical regimen. Using this approach, they were able to demonstrate improved clinical outcomes in a group of veterans with chronic illnesses.

Davis found that only 19 percent of 500 Web sites representing common illnesses or conditions were accessible for users with visual impairments who used automated screen readers (2002, TR#54). He also notes that almost 65 percent of the Web sites that failed the accessibility test had just a single type of fixable problem. Davis further points out that the best way to make sure a Web site is accessible is to do so from the beginning by following established guidelines, such as those described in Chapter 2 and Appendix 1.

In sum, there appears to be a bias in the literature toward studying those persons who have easy Internet access, can use readily available technologies without adaptation, and do not need much if any technical support. Identifying ways to include currently excluded or understudied groups in future research is critical to creating an evidence base of results that can be generalized as well as specified for select user groups.

Availability

In addition to technology access, people must also have available the information and tools they want and need—that is,

meaningful access. Because the Internet seems to be an "always on," universally available channel, there is often the assumption that posting something on the Internet automatically increases information availability. Developing a Web site that contains relevant information is not enough, however, if people cannot locate the site. The studies discussed below suggest that research on information-seeking behaviors is still needed to understand how well different groups can locate health information and tools. (See Chapter 2 for additional information on health information-seeking issues.)

One approach to assessing availability is to go directly to the target audience to conduct a needs assessment. For example, Rozmovits and Ziebland conducted focus groups and interviews with people who had breast or prostate cancer (2004, TR#72). They found that cancer patients had information needs that changed during the course of their illness, and they were not always able to find the information they wanted. Similarly, Goldsmith, Silverman, and Safran found through formative research that parents of children with cancer reported a primary need for help with medication management (2002, TR#60).

Understanding the strategies that people use to locate information is key. Eysenbach and Kohler observed study participants as they tried to locate answers to specific researcher-generated health questions using the Internet (2002, TR#58). They found that although all 16 participants used search engines as starting points and somewhat

suboptimal search strategies, they were able to find answers to the questions. However, the researchers did not provide an analysis of the accuracy of the answers or ascertain whether the participants were satisfied with the information they found.

The Pew Internet & American Life Project's 2005 report on search engine use found that 84 percent of Internet users have used search engines, 92 percent of those who use search engines are confident about their searching ability, and 87 percent report successful search experiences most of the time (Fallows, 2005, TR#59). Some user groups, however, have special challenges related to information-seeking. Zarcadoolas, Blanco, Boyer, et al. examined the navigation skills of adults with low literacy and identified several factors that affect availability for this group (2002, TR#81). These include spelling problems that interfere with searching, difficulty entering Web addresses, and difficulty using navigational tools such as graphic links, back arrows, and scrolling.

Appropriateness

Users can have access to technology and the skills to locate information and tools, but still encounter issues related to appropriateness. Appropriateness refers to the fit between the user and the tool. In an attempt to assess appropriateness, researchers have conducted studies on cultural relevance, users' perceptions of the credibility of content, content analyses focused on information quality and readability, and the use of tailoring.

Cultural Relevance

Few of the reviewed studies specifically examined cultural relevance or recruited samples based on racial and ethnic characteristics. Most of the studies did include members of the target audience segmented by age (e.g., college students) or by health or disease status (e.g., women with breast cancer, people at risk for heart disease). Only a few studies conducted research with members of specific ethnic groups to assess cultural relevance (e.g., Campbell, Honess-Morreale, Farrell, et al., 1999, TR#4; Duncan TE, Duncan SC, Beauchamp, et al., 2000, TR#41; Jantz, Anderson, and Gould, 2002, TR#45); Zimmerman, Akerelrea, Buller, et al., 2003, TR#82).

Users' Perceptions of the Credibility of Content

Measuring users' perceptions of the credibility of available information is another means to assess appropriateness. Rozmovits and Ziebland found that study participants were aware of the credibility issues surrounding health information on the Internet, and reported that they often compared information from several different sources before taking it as fact (2004, TR#72). These users preferred information about cancer treatment from noncommercial sites and specifically from institutions with good reputations, such as universities or medical centers.

Eysenbach and Kohler found that users identified many criteria for establishing credibility, such as the source of the information, a professional layout, understandable and professional writing, and citation of scientific evidence (2002, TR#58). Similar to Rozmovits and Ziebland's findings, a few users felt that it is easier to assess information quality on the Internet because they could cross-check information on different sites. When they were actually observed searching for information, none of the participants checked the source of the information and fewer than 25 percent could even tell the broad category of the site they used (e.g., university, Government agency, business).

Barnes, Penrod, and Neiger found a similar disconnect between what users reported as important factors to consider when establishing credibility and actual behavior in assessing Web site quality (2003, TR#46). Walther, Wang, and Loh found an interaction effect of advertisements on user perception of credibility (2004, TR#36). The presence of advertisements on sites with .org domains made the site appear less credible than ads on sites with .com or .edu domains.

Physicians or other healthcare providers could serve as intermediaries to direct patients to appropriate Internet content. The study by D'Alessandro, Kreiter, Kinzer, et al. had physicians provide information prescriptions to patients that contained relevant Internet sites for health information (2004, TR#8). One-third of participants used these prescriptions and were then more likely to state that they would use them again and had already recommended them to others.

Content Analysis

Researchers also assess appropriateness, particularly of publicly available Web sites, by conducting content analyses of the information and performing readability analyses. The overall goal is to measure information quality. Inconsistent findings are reported related to Web site quality. For example, a study by Madan, Frantzides, and Pesce (2003, TR#87) on laparoscopic bariatric surgery and a study by Fahey and Weinberg (2003, TR#85) on LASIK (laser-assisted *in situ* keratomileusis) eye surgery found that the information on the Web in both of these areas was poor and unreliable. One study on diabetes sites found that information quality varied widely (Seidman, Steinwachs, and Rubin, 2003, TR#91). Oermann, Lowery, and Thornley reported that better quality content was found on Web sites sponsored by a university, professional organization, medical center, or Government agency (2003, TR#90). Only the study by Cheh, Ribisl, Wildenmuth, et al. on smoking cessation Web sites found that a majority of the information was accurate (2003, TR#83).

Evers, Prochaska, Prochaska, et al. examined the quality of Internet programs designed to help users change behavior in seven key areas: tobacco use, physical activity, alcohol, diet, diabetes, depression, and pediatric asthma (2003, TR#84). Of the 273 sites examined, only 42 (15 percent) met four of the five minimum criteria determined to have the potential to change behavior. These 42 sites then underwent a full review. All included self-assessments and some form of contact. Only 12 percent included individually tailored feedback, and none included information about

evaluation for effectiveness, which was a key recommendation of the 1999 Science Panel on Interactive Communication and Health.

Content readability is usually assessed using readability formulas that provide grade-level assessments. Birru, Monaco, Lonelyss, et al. (2004, TR#48), Kusec, Brborovic, and Schillinger (2003, TR#64), and Oermann et al. (2003, TR#90) found that the average reading levels of the sites they examined was at a 10th-grade level. Birru et al. found some methodological difficulties assessing respondents' comprehension of information on the Internet (2004, TR#48). For example, some respondents could correctly answer interviewers' questions on the content by reciting directly from the Web site. However, when prompted, respondents could not put the answers in their own words. This finding is not surprising because readability analyses do not provide much insight into users' understanding of the content and their capacity to apply the information to specific circumstances. (See Chapter 2 for additional discussion of health literacy issues.)

Eysenbach and Kohler conducted a systematic review of studies that assessed the quality of health information on the Internet (2002, TR#58). Differences in study methodology and quality criteria were used in the reviewed studies, a fact that could explain differences in study results and conclusions. For example, they found that many studies assessed completeness of information; however, this approach generally did not take into account the context or stated purpose of the site or links provided to additional information. They point out that the Internet is not the

only type of media delivering information of inconsistent quality, and thus must be considered against the "background of imperfect consumer health information in other media" (p. 2697). One strategy they recommend includes improving the user's ability to locate credible sites and to filter out inadequate ones.

Tailoring

As Chapter 2 indicates, tailoring is thought to be one of the most promising methods to improve the appropriateness of content for users because tailoring simulates an individualized assessment and response. Several tools in the behavior change area evaluated tailored information and feedback using randomized controlled trials (Bernhardt, 2001, TR#3; Campbell et al., 1999, TR#4; Oenema and Brug, 2003, TR#25; Oenema et al., 2001, TR#26). All these trials involved tools tailored to the user's stage of readiness to change. Other tailoring variables included knowledge, dietary intake and habits, awareness of dietary intake as compared with published guidelines, and perceived overweight. These studies all showed positive effects for the tailored information as compared to the control conditions.

In general, the study findings that address appropriateness indicate that users may find it difficult to connect with tools that fit their interests and needs. The success of tailoring suggests the need for much greater attention to the design and testing of elements that make tools a better fit in terms of cultural relevance, consistency, comprehensiveness, and understandability for diverse users.

Acceptability

Acceptability refers to whether people find the tools satisfactory. Satisfaction is typically one criterion that is applied to the evaluation of commercial tools. The fact that millions of people are actively seeking health information online and the phenomenal increase in Internet use speak to a high initial level of acceptability. Researchers and tool developers have focused on usability studies to gauge and improve acceptability, recognizing it as a necessary condition for the ultimate success of e-health tools. Examining use over time can provide an additional measure of acceptability in that it makes it possible to gauge ongoing satisfaction with or usability of programs based on whether people continue to use them.

Ease of Use

Studies of e-health tools designed for a variety of purposes generally found that users report they are easy to use, although some studies found that this was not always the case. Block, Miller, Harnack, et al. reported that 97 percent of users found a nutrition education program easy to use (2000, TR#49). Feil et al. reported that 63 percent of users rated their smoking cessation Web site "easy" or "very easy" to use (2003, TR#10). Some users commented that the smoking cessation site used in the study by Lenert and Cher was complex and difficult to navigate (1999, TR#65). Oenema et al. found that those who had less familiarity with computers also found their tailored program more difficult to use (2001, TR#26).

People using e-health tools designed to allow access to medical records and/or to provide a means to communicate electronically with their healthcare providers were able to use these tools. Participants were able to master the complex login procedures required for privacy and to use the systems effectively; however, these users tended to be more educated, have personal computers, and be covered by a private health insurer (Cimino, Li, Mendonca, et al., 2000, TR#51; Hassol, Walker, Kidder, et al., 2004, TR#62; Masys, Baker, Butros, et al., 2002, TR#68). Sciamanna and Clark examined the acceptability of a fingerprint reader as an alternative means to authenticate users in a medical clinic, thus eliminating the need for complex login procedures (2003, TR#31). Those who used the fingerprint reader did not appear to under-report information and had fewer concerns about the reader than did those who did not use the reader.

More difficulties were found when the study populations were chronically ill, elderly patients with little or no computer experience. Caregivers of patients with dementia generally found the telephone-linked support system easy to use, but a small percentage of users had difficulty reading the screen or hearing the messages (Czaja and Rubert, 2002, TR#53). Kaufman et al. found that the use of the computer mouse for a diabetes home telemedicine system was exceedingly difficult for some of their elderly participants (2003, TR#63). Furthermore, all of the novice users experienced difficulty in developing a coherent mental model of the system and were frustrated by their inability to navigate screen transitions.

McKay, Glasglow, Feil, et al. found that the diabetes self-management component of their Web site, which guided participants in tracking blood glucose levels throughout the day, was not used often (2002, TR#21). They concluded that the tool might have been too complex for participants to use regularly. The VA program by Ryan et al. that matched technology to user ability found that patients were highly satisfied with the technology and 95 percent of users rated their technology "easy to use," indicating that with careful selection of technology, these types of problems can be solved (2003, TR#73).

Satisfaction

Self-reported satisfaction levels have been high for tools across a wide range of purposes. People showed high levels of receptivity to e-health tools to aid decisionmaking for the treatment of benign prostatic hypertrophy (Lenert and Cher, 1999, TR#65), genetic testing for breast cancer (Green, Peterson, Baker, et al., 2004, TR#14), and contraceptive use (Chewning, Mosena, Wilson, et al., 1999, TR#6).

Healthcare tool users were also very satisfied. Liederman and Morefield found that 78 percent of their sample of RelayHealth users rated Web messaging "better" or "much better" than calling their doctor, and they reported that electronic communication improved access to their practitioner (2003, TR#67). Tang, Black, Buchanan, et al. found that patients using the PAMFOnline system (Palo Alto Medical Foundation) rated online messaging highly, even though a subscription fee

was associated with this function (2003, TR#76). The researchers also found that the majority of users identified getting lab results as the most important benefit of having access to their medical records (2003, TR#76). Hassol et al. surveyed members of the Geisinger Health System who were "early adopters" of the MyChart application (2004, TR#62). They reported that patients saw online communication as especially useful for general medical questions or prescription renewals.

Constraints of the technology at times affected satisfaction. Liederman and Morefield found that satisfaction with Web-based messaging correlated with response time (2003, TR#67). Those who felt they received a timely response to their messages were "very satisfied" (74 percent) with the system; likewise, those who reported a slow response from the clinic were dissatisfied (6 percent). Patients used the telephone when the electronic system was not in place yet, when they wanted quicker responses, or when it was easier to explain the problem orally than in writing.

Others liked using e-health tools as an adjunct to medical care in physicians' offices or clinics. Wilkie, Huang, Berry, et al. found that patients liked using computerized assessments to help assess their levels of pain and fatigue (2001, TR#78; Wilkie, Judge, Berry, et al., 2003, TR#79). Patients reported that the tool gave them the ability to describe their pain more specifically, enabling better discussions with their physicians.

In addition, surveys conducted with people who use online health communities show that they identify many advantages

of online community use. For example, groups are available 24 hours a day, 7 days a week (Han and Belcher, 2001, TR#61; Shaw, McTavish, Hawkins, et al., 2000, TR#74). They do not have to be concerned about their appearance (Shaw et al., 2000, TR#74) or other issues related to attending face-to-face groups (Shaw et al., 2000, TR#74; Czaja and Rubert, 2002, TR#53). They perceive equalized participation among group members due to anonymity (Colvin, Chenoweth, Bold, et al., 2004, TR#52) and the lack of social context cues, such as dress or appearance (Shaw et al., 2000, TR#74).

Other advantages are that people also can exchange information (Finn, 1999, TR#86; Mendelson, 2003, TR#89); share personal feelings (Shaw et al., 2000, TR#74), support, and coping strategies (Mendelson, 2003, TR#89); feel less alone (Reeves, 2000, TR#71; Shaw et al., 2000, TR#74) and less depressed (Lieberman, Golant, Giese-Davis, et al., 2003, TR#66); help others (Reeves, 2000, TR#71); and gain feelings of empowerment (Finn, 1999, TR#86; Reeves, 2000, TR#71). Preece, Nennecke, and Andrews found that people who posted to online communities had a greater sense of belonging and satisfaction than people who visited the communities but did not post (2004, TR#69).

Online community users do report some disadvantages, such as the time commitment needed to review large volumes of postings (Han and Belcher, 2001, TR#61; Shaw et al., 2000, TR#74), a lack of physical contact or proximity to other group members (Colvin et al., 2004, TR#52; Han and Belcher, 2001, TR#61), dealing with "noise" or off-topic postings, and the generation of negative

emotions because they were exposed to others' losses or problems (Han and Belcher, 2001, TR#61). Technical problems, such as difficulty with posting, can also be a disadvantage (Colvin et al., 2004, TR#52; Lieberman et al., 2003, TR#66).

Users were generally satisfied with tools designed to help them adopt healthier behaviors. For example, Lenert and Cher reported that 94 percent of the users of their smoking cessation site felt the site had helped their quit effort (1999, TR#65). In a tailored nutrition program, 79 percent of users reported that the program was helpful and most would use it again (Campbell et al., 1999, TR#4). About 90 percent of users of a nutrition education program reported that they had learned something new and would recommend the program to others (Block et al., 2000, TR#49). In a study by Woodruff, Edward, Conway, et al., 95 percent of teens would recommend the smoking cessation site to other teen smokers (2001, TR#80). McKay, King, Eakin, et al. found that the users in the intervention group were more satisfied with an intervention designed to increase levels of physical activity than were users in the computer-based information-only control group (2001, TR#22).

Only one reviewed study reported participants' negative feelings about an Internet group (Harvey-Berino, Pintauro, and Gold, et al., 2002, TR#16). The researchers found that people preferred in-person groups for weight-loss maintenance rather than Internet groups; however, all of these participants had previously attended in-person weight-loss groups.

In contrast, McKay et al. found that nearly 60 percent of patients with diabetes in primary care practices were willing to participate in a computer-based diabetes management intervention (2002, TR#21). They believe this reflects a substantially higher percentage than would be willing and able to attend traditional educational programs.

Most surveys of satisfaction examine the tools as a whole. The study by Weis, Stamm, Smith, et al. of users of a site for persons with multiple sclerosis examined satisfaction with components of the site (2003, TR#77). They found that, in general, users preferred the information functions to the support functions of this site. Users who used both functions gave the site the highest overall ratings. Women rated the information function higher than did men; adults with children rated all functions higher than did those without children; and younger users rated the support functions higher than older users did. Escoffery, McCormick, Bateman, et al. also found that participants who used their smoking cessation site preferred the informational components to the "ask the expert" and message board features (2004, TR#57).

Usage Over Time

Studies that monitored login rates showed that logins were most frequent in the beginning of the intervention. They also found that participants used the programs less frequently and/or did not complete all modules as time passed (Clarke, Reid, Eubanks, et al., 2002, TR#7; Glasgow et al., 2003, TR#13; Irvine, Ary, Grove, et al., 2004, TR#17; McKay et al., 2001, TR#22; McKay et

al., 2002, TR#21; Pinto et al., 2002, TR#27; Tate et al., 2001, TR#34; Tate et al., 2003, TR#33). Four studies found evidence of a dose-response relationship, with increased use leading to better outcomes (Celio, Winzelberg, Wilfley, et al., 2000, TR#5; Delichatsios et al., 2001, TR#9; Frenn, Malin, Bansal, et al., 2003, TR#42; McKay et al., 2001, TR#22). However, Pinto et al. did not find this effect (2002, TR#27).

Although the decline in usage may indicate some level of dissatisfaction, users in the intervention groups had higher login rates than persons in the computer-based control groups throughout the duration of the studies (McKay et al., 2001, TR#22; Tate et al., 2001, TR#34; Tate et al., 2003, TR#33). Further, the studies by Glasgow et al. (2003, TR#13) and McKay et al. (2002, TR#21) used multiple intervention groups. Similarly, they found that not only did the intervention groups use the program more than the control groups, but also the intervention groups that included a social support component had more logins than the other intervention groups.

There is almost no information on how this decrease in utilization compares to what might occur in traditional face-to-face interventions. The only exception is that McKay et al. reported that their dropout rate of 16 percent was "somewhat" higher than a similar intervention conducted in person (2002, TR#21).

Researchers identify several factors with the sites and users that might have caused attrition. Participants in a study by Napolitano et al. reported that because

the Web site did not change over time, they did not need to return (2003, TR#23). Lenert and Cher reported that their site was too complex, relied too heavily on text, and required too much self-direction to locate pertinent information (1999, TR#65). They further hypothesized that people who enroll in an Internet-based program may not be as committed as those who enroll in traditional face-to-face interventions. McKay et al. thought that the Internet might be more conducive to surfing behavior and less to use of a single site (2001, TR#22). Developing Web sites that keep users coming back is a challenge (Glasgow et al., 2003, TR#13), and more research is needed to determine how to stimulate ongoing use (McKay et al., 2001, TR#22).

Other studies have identified some strategies that can be used to attract and keep users. Bowen, Ludwig, Bush, et al. found that the use of e-mail cues increased the number of women who logged in to a breast cancer information site (2003, TR#50). They found that the most common reason for nonusage was finding the time to get online. Feil et al. found no difference in attrition between groups receiving a $10 incentive and groups receiving a $20 incentive, and no difference in response to follow-up using either e-mail or regular postal service reminders (2003, TR#10). Although large numbers of people search the Internet and see many advantages to the Internet as a channel for health information, research has yet to focus on what will hold the interest of diverse sets of users and motivate them to return to a tool again and again.

Applicability

Applicability is related to utility and outcomes. Because most research studies treat e-health tools as an intervention, studies typically are designed to measure the impact of the tools on a wide range of outcomes, ranging from changes in knowledge to health status. Many different types of tools were found to produce different types of positive outcomes. The findings summarized here are from studies using control group comparisons, either in randomized clinical trials or quasi-experimental designs. Only one study involved the evaluation of a commercial Web site (Womble, Wadden, McGuckin, et al., 2004, TR#38).

Knowledge and Information Needs

e-Health tools have been found to increase knowledge in a wide range of areas, including:

- Nutrition knowledge in low-income African American women (Campbell et al., 1999, TR#4) and low-income Hispanic women (Jantz et al., 2002, TR#45)

- Skin cancer causes and prevention in children (Hornung, Lennon, Garrett, et al., 2000, TR#43)

- Breast cancer in low-income Hispanic women (Valdez et al., 2002, TR#35; Green et al., 2004, TR#14)

- Alcohol use and effects in college students (Reis, Riley, Lokman, et al., 2000, TR#29)

- HIV prevention in adolescent girls (DiNoia, Schinke, Rena, et al., 2004, TR#40)

- Oral contraceptives in adolescent girls (Chewning et al., 1999, TR#6)

- Asthma in children (Krishna, Francisco, Balas, et al., 2003, TR#18; Lieberman, 2001, TR#19) and their caregivers (Krishna et al., 2003, TR#18)

Gustafson et al. found that race, education level, and insurance status interacted with use of CHESS (2001, TR#15). This system helped women of color, more than Caucasian women, to overcome the perception of unmet information needs and increase their perception of participation in their own health care. Education levels and health insurance status were found to interact in the same way as race and ethnicity, with women with less education and less health insurance receiving more benefit. McTavish et al. found that women of color used a CHESS discussion group differently than white women in that the communications by women of color focused more specifically on information about breast cancer and its treatment, whereas white women were more likely to discuss daily life or offer mutual support (2003, TR#88).

Attitudes and Beliefs Theorized to Mediate Behavior Change

Positive changes in attitudes and beliefs were seen in the following areas as a result of interacting with e-health tools:

- Increased self-efficacy for

  — Improving dietary habits in adults (Anderson et al., 2001, TR#1; Irvine et al., 2004, TR#17)

  — Protecting self from HIV in college students (DiNoia et al., 2004, TR#40)

— Refusing marijuana in high school students (Duncan et al., 2000, TR#41)

— Self-managing asthma in children with asthma (Lieberman, 2001, TR#19)

— Self-managing diabetes in children (Lieberman, 2001, TR#20)

- Increased intention to

— Change eating habits in adults (Irvine et al., 2004, TR#17; Oenema and Brug, 2003, TR#25; Oenema, Brug, and Lechner, 2001, TR#26)

— Refuse marijuana in high school students (Duncan et al., 2000, TR#41)

— Ask physician about mammograms in Latina women with low incomes and limited education (Valdez et al., 2002, TR#35)

- Affect motivational readiness to change related to

— Eating behaviors in low-income, primarily African American women (Campbell et al., 1999, TR#4)

— Physical activity in sedentary adults (Napolitano et al., 2003, TR#23; Pinto et al., 2002, TR#27)

- Affect outcome expectations related to

— Healthier eating in adults (Anderson et al., 2001, TR#1)

— Alcohol use in college students (Reis et al., 2000, TR#29)

— Oral contraceptive use in white and African American, sexually active adolescents (Chewning et al., 1999, TR#6)

- Increased positive attitudes and decreased barriers about skin cancer

prevention in elementary school students (Hornung et al., 2000, TR#43) and college students (Bernhardt, 2001, TR#3)

- Increased realistic perceptions about food intake (Oenema and Brug, 2003, TR#25)

- Decreased misperceptions about peer drinking in college students (Neighbors et al., 2004, TR#24)

- Decreased weight and shape concerns in college students (Celio et al., 2000, TR#5)

Social Support

Two randomized controlled trials measured perceived social support and showed that it can be affected (Barrera et al., 2002, TR#2; Gustafson et al., 2001, TR#15). One of these studies examined a multifunctional program (CHESS), so the relative contribution of the support components cannot be determined (Gustafson et al., 2001, TR#15). Barrera et al. found that those in the support conditions (social support alone and combined social support with coach) increased their perceptions of the availability of social support as compared to the information-only control group or the group that had access to a "personal coach" (2002, TR#2).

Decision Support

Two studies examined decision support tools designed to be used as an adjunct to clinical care. Green et al. studied the effect of using a computer-based decision aid about breast cancer susceptibility and genetic testing (2004, TR#14). Those in

the intervention group interacted with the computer and received genetic counseling; the control group received only genetic counseling. After using the computer program, women with a low risk of breast cancer were able to reduce their perceived risk of getting breast cancer and their intention to undergo genetic testing, and this perceived risk was further reduced after the genetic counseling session. At baseline, more than 80 percent of women in both groups indicated their intention to receive genetic testing; at follow-up, only 19 percent had actually undergone testing.

Chewning et al. studied the effect of a computer-based contraceptive decision aid designed to promote effective selection and contraceptive use in sexually active adolescent girls during visits to family planning clinics (1999, TR#6). The decision aid was evaluated in two clinics, one with a primarily Caucasian population (Madison, Wisconsin) and the other with a primarily African American population (Chicago, Illinois). They found that significantly more of those in the intervention group in Chicago followed through with their intention to use oral contraceptives as compared to the Chicago control group, with a similar but statistically nonsignificant trend in Madison.

Health Behaviors

Use of specific e-health tools has been shown to affect health behaviors as follows:

- Improve dietary habits in

  — Adult supermarket shoppers (Anderson et al., 2001, TR#1)

  — Adult workers (Irvine et al., 2004, TR#17)

  — Adults with type 2 diabetes (Glasgow et al., 2003, TR#13; Glasgow and Toobert, 2000, TR#12; McKay et al., 2002, TR#21)

  — Sedentary adults (Delichatsios et al., 2001, TR#9)

  — Low-income, primarily African American, women (Campbell et al., 1999, TR#4)

  — Middle school students (Frenn et al., 2003, TR#42)

  — Elementary school children (Baranowski et al., 2003, TR#39)

- Increase physical activity in

  — Sedentary adults (Napolitano et al., 2003, TR#23; Pinto et al., 2002, TR#27)

  — Adults with type 2 diabetes (McKay et al., 2001, TR#22)

- Reduce drinking in heavy-drinking college students (Neighbors et al., 2004, TR#24)

- Decrease disordered eating behaviors in college students (Celio et al., 2000, TR#5)

- Increase adherence to

  — Medical protocol in adults with congestive heart failure (Ross, Moore, Earnest, et al., 2004, TR#30)

  — Asthma action plans (Finkelstein et al., 2001, TR#11)

Two studies compared their findings to objective outcome goals. Although Baranowski et al. (2003, TR#39) and Frenn

et al. (2003, TR#42) found that they were able to positively impact the dietary habits of study participants, the improvements were not enough to meet dietary guidelines.

Health Outcomes

Researchers have used a variety of e-health tools to affect health outcomes. The results, which are mixed, are summarized in the following.

Weight Loss. Two studies by Tate et al. found that an Internet-based weight-loss program led to significant weight loss in overweight adults (2001, TR#34; 2003, TR#33). Harvey-Berino et al. found no difference in weight loss between those using an online program as compared to those attending an in-person group (2002, TR#16). Womble et al. compared weight loss in overweight women who were randomly assigned to use a commercial dieting site (*eDiets.com*) or a weight-loss manual (2004, TR#38). In the strictest analysis of data, they found that the group using the manual lost significantly more weight than the group using *eDiets.com*.

Pregnancy. In a study of contraceptive use, there were no differences between control and intervention groups in the discontinuation of oral contraceptives. There was a statistically nonsignificant trend toward decreased pregnancy in Madison for those who used the computer-based decision aid, but no difference between groups in the Chicago sample (Chewning et al., 1999, TR#6).

Mental Health and Quality-of-Life Outcomes. Proudfoot et al. found

decreased levels of depression and anxiety in people with those conditions (2003, TR#28). Clarke et al. found no effect of their Internet program on depression; however, process evaluation showed low usage of the program overall (2002, TR#7). Winzelberg et al. found significant changes in measures of depression, stress, and cancer-related trauma in women with breast cancer, but no difference in anxiety or coping for women (2003, TR#37). A possible explanation is that the intervention was not designed to affect these measures directly. Smith and Weinert found no differences between study groups on psychosocial and quality-of-life measures in women with diabetes, although this may be due to a small sample size (2000, TR#32). The participants did report that the project provided a great deal of support and feelings of connectedness. No changes in quality-of-life measures were found in adults with type 2 diabetes (Glasgow and Toobert, 2000, TR#12). Both groups (*eDiets.com* and manual) in the study by Womble et al. showed improvements in quality-of-life measures and less depression during the course of the study, but there were not significant differences between the groups (2004, TR#38).

Physiological Measures. Modest changes were found in cholesterol and lipid ratios along with small reductions in glycosylated hemoglobin (HbA1c) levels in adults with type 2 diabetes (Glasgow et al., 2003, TR#13; Glasgow and Toobert, 2000, TR#12), but no change was found in these measures in a study by McKay et al. (2002, TR#21). No difference was found in blood pressure, glucose, lipids, or lipoproteins

between groups in the Womble et al. (2004, TR#38) study.

Possible Negative Outcomes

Some researchers have posited possible negative effects, such as increased depression or social withdrawal, from Internet use. Several studies show that those who seek help in online communities may have more serious conditions than those who do not (Beebe, Asche, Harrison, et al., 2004, TR#47; Epstein, Rosenberg, Grant, et al., 2002, TR#55; Erwin, Turk, Heimberg, et al., 2004, TR#56; Houston, Cooper, and Ford, 2002, TR#44). However, these studies were not randomized controlled trials. It is not clear that Internet use is the cause of this greater impairment. It is equally possible that those who need support and lack it in their face-to-face relationships are trying to attain support via the Internet (Beebe et al., 2004, TR#47).

Another area of concern relates to the possibility that patients could become distressed or anxious by something they read as a result of having electronic access to their medical records (Tang et al., 2003, TR#76; Masys et al., 2002, TR#68). Tang et al. used hyperlinking to link medical terms to a dictionary to improve patient understanding, but they did not evaluate the impact of this feature (2003, TR#76). Masys et al. set up safeguards, including a toll-free hotline number, to protect patients; however, they found that this concern was unfounded for this group of participants (2002). Participants using SPPARO (System Providing Patient Access to Records Online), a Web-based online medical record, did not report any negative effects (Ross et al., 2004, TR#30).

Cost Savings and Return on Investment

Although not part of the "Five A's" framework, described at the beginning of this chapter, the effect of e-health tools on costs and return on investment for healthcare organizations, insurers, employers, and the Government is of strong interest in the policy and healthcare communities.

Researchers are beginning to calculate the financial impacts of the use of e-health tools. Krishna et al. provided evidence that using an e-health tool for asthma self-management education is cost-effective (2003, TR#18). This study showed reductions in emergency department visits in the intervention group that translated into a savings of approximately $907.10 per child as compared with a savings of only $291.40 per child for the control group. Other indirect savings were discussed but not calculated. For example, the children in the intervention group used a significantly lower average dose of inhaled corticosteroids by their third clinic visit, thus leading to a reduction in medication expenditures. In addition, they reduced school absences during the study period by an average of 5.4 days per child per school year as compared with 1.6 days for children with asthma in the control group. These indirect savings would be realized by working parents and their employers.

In a randomized clinical trial, 59 children and adolescents, age 8 to 16, improved their self-care and reduced their emergency clinical utilization after playing Packy & Marlon, a health education and disease management video game (Lieberman, 2001,

TR#20). They reduced diabetes-related urgent and emergency visits by 77 percent after 6 months of access, compared to no reduction in clinical utilization in a control group of youngsters with diabetes who used an entertainment video game with no health content.

Ross et al. found no difference in hospitalizations or mortality between patients who used SPPARO and those who did not have access (2004, TR#30). Those who used SPPARO did have more emergency department visits; however, these did not temporally relate to use of SPARRO.

e-Health tools can also result in savings by enabling patients to perform monitoring tasks that professionals would do. For example, Finkelstein et al. demonstrated that lung function test results collected during home asthma telemonitoring were comparable to those collected under the supervision of trained professionals (2001, TR#11).

SUMMARY AND DISCUSSION

This chapter provides a review of recent research pertaining to e-health tools and factors affecting their use by diverse population segments. Overall, the research continues to inspire a sense of promise for these tools as many positive findings have been reported across different categories of tools with a wide variety of components. The lack of diversity in the samples used in these studies, however, makes very clear one of the key messages of this report. The body of knowledge about which groups will engage with and benefit from e-health implementation is thin and must be developed using a model of diversity if the tools are to achieve their potential as public health interventions. This section summarizes the research reviewed in this chapter and examines the limitations and challenges of current research.

The Body of Research

Existing research on e-health tools clusters around two broad areas: (1) evaluation of public domain e-health tools and Internet use, and (2) development and evaluation of specific tools developed and tested in research settings. Research on tools in the public domain includes quality assessments and readability analyses of online content, content analyses of online communities, and surveys and observations about how people use the Internet.

The general public appears satisfied with the information and support online; however, content analyses find that the quality of the information is less than optimal. Furthermore, readability and other access issues may make online use difficult for members of diverse populations. Evaluation of e-health tools can benefit users by improving the quality and effectiveness of the tool, minimizing the chance of harm, promoting innovation in the tools, conserving resources, and allowing users to make informed choices about tools (Eng, Maxfield, Patrick, et al., 1998). Only one study evaluated a widely available commercial e-health tool (*eDiets.com*) in a randomized controlled trial, the results of which were not favorable.

The second broad area of research focuses on the development and evaluation of specific e-health tools. These studies provide information about the usability, efficacy, and effectiveness of the tools. The quantity and quality of the research is uneven across topics and tools. Some areas, such as tools for behavior change, are theory-based and have generated sound research and evaluation to support their use. Many multiple randomized controlled studies across several health topics have found positive outcomes. Other tools, such as healthcare tools, that are emerging in response to market and policy demands do not yet have much of a scientific basis to suggest that they will have their intended effect. Most of the research on these tools is focused on satisfaction and usability.

Unfortunately, many research-based tools are not widely distributed or easily accessed by the general public. It is important to bring evidence-based e-health tools to those who can benefit from them. The reverse is also true. It is just as important to use the findings about what people actually need, desire, and do while online to guide the development of research-based e-health tools. Much work remains to be done to bridge the gaps between these areas. Chapter 4 discusses this topic in greater detail.

The Tools

Although the literature review and the scan of tools in the field identified a large number of tools, there are no standard, accepted definitions for purposes or components of tools for consumers. In general, the tools tend to be multicomponent programs that have been designed for many purposes: to inform, provide support, aid behavior change, assist decisionmaking, help manage disease, and facilitate interaction with the healthcare system. Some research studies clearly describe the tool being studied; others provide only vague descriptions. Some tools with similar stated purposes have notably different components. The wide range of tools reflects the array of burgeoning and exciting possibilities that can be offered through electronic media, but it also makes the comparison of different studies and future replications difficult.

More needs to be known about e-health tools, including the identification of critical components and combinations of components as well as the optimal conditions for use of these tools. Individual studies may answer one or two questions about use, but there is not yet a body of research that indicates who should use these tools, when, where, how frequently, and how intensively. Factors that lead to user adoption and ongoing use as well as factors that lead to attrition also need to be identified.

It is encouraging that many studies have found positive changes in knowledge and intention after just one interaction. Findings on actual behavior change and health outcomes have been less clear. However, many of these studies may not have provided interventions with enough frequency or intensity to bring about desired changes in these areas.

Key Findings of the Review by Access, Availability, Appropriateness, Acceptability, and Applicability

Access

Millions of people are using the Internet for health-related purposes, and estimates can be made about the deployment of e-health tools in large, closed systems, such as the VA's My Health*e*Vet. Beyond this, little is known about actual uptake and use of e-health tools. Few if any data exist on the distribution of e-health tools across the population or within subgroups. Population and subgroup data on level of interest in and attention to these tools also are not available. Large numbers of e-health tools have been developed, but it is not known how many people know about these tools, how many are using these tools, and how many could be influenced to try them. The ability of interested users to locate and access these tools, particularly those with a credible research basis, is also unknown.

Availability

A major issue that emerges from this review is the limited external validity of much of the research, as so many of the studies utilized convenience samples or required computer ownership. This approach has led to a disproportionate amount of information on Caucasian women with higher education. Even when studies reported the demographics of their samples, most did not analyze their findings according to these variables. A few exceptions exist, such as the findings from CHESS, in which women

of color, women who were less educated, and women with less health insurance appeared to derive greater benefits from interacting with CHESS (Gustafson et al., 2001, TR#15). Similarly, Oenema and Brug found that respondents with less education seemed to have benefited more from the tailored nutrition feedback than did those with higher education (2003, TR#25). Frenn et al. also found evidence that their intervention had a differential effect based on race and gender of users (2003, TR#42). The lack of diversity in the research samples and evidence of differential effects based on demographics suggest major gaps in our knowledge about how to address issues of access as well as the acceptability and appropriateness of personal e-health tools for diverse segments of the population.

Appropriateness

Some tools have been recently developed that target special populations, and some of these were developed with input from the target audience. These studies show that with careful attention to cultural, literacy, and technological needs, successful tools can be developed for and used within these subpopulations (Campbell et al., 1999, TR#4; Jantz et al., 2002, TR#45). User-centered design and usability research, along with participatory research methods, can be used to bridge the gap between what designers and researchers envision and what the ultimate end users actually find engaging and helpful. It is critical to seek input about the diverse needs of all potential users during tool development and ensure that they are represented in the evaluation studies.

Any review in this area should consider how technology is used in the research projects. The studies that required participants to use their own computers found that the capabilities of users' technology can vary tremendously. At times, researchers have found that participants were not always able to access all parts of the programs being tested. These kinds of studies are important because they help determine the feasibility of delivering e-health tools over the Internet. Other studies had participants interact with an e-health tool in a lab or clinical setting. This allows for potentially greater representation in the study sample, helps minimize potential technical problems, and gives an idea of the efficacy of a tool, that is, its success under very controlled conditions. Information from both of these kinds of studies is important for building the knowledge base for e-health tools.

Acceptability

Findings from the studies in the Acceptability section reveal that people like e-health tools and generally find them easy to use. There does seem to be a decline in usage over time, but the declines were not as steep as those found in the control conditions. It is not known how this decline compares to other intervention formats, such as in-person educational or therapeutic programs. Several researchers have ideas about why dropoffs occur; they posit that sites are too complex or not dynamic enough. Research will need to continue to investigate these factors. A research path would be to examine what personal qualities lead to preferences for online interventions or whether differences exist between those who seek help online and those who seek face-to-face interventions.

Applicability

The studies in this section found many positive findings, but some design issues deserve further mention.

Measures. These studies showed a strong reliance on self-reported data to document change. Typically, self-reported data are considered weaker than other types of objectively collected data and subject to bias. Because participants tend to make their responses more socially desirable, the effects may be overstated. Also, many of the studies use questionnaires or adapt existing questionnaires without reporting reliability or validity. This could affect findings in unknown ways. To establish firmly the effectiveness of these tools, researchers must continue to develop and utilize objective, reliable, and valid measures.

From a health literacy perspective, an equally important issue may be the mismatch in understanding between researchers and study participants about what is being measured. The health literacy construct highlights the frequent gap in understanding between health professionals and nonprofessionals. Particularly when the use of technology is involved, attitudes, beliefs, and expectations may play an important role in shaping how users interact with the systems and report data.

Frequency, Duration, and Intensity. The studies examined a variety of tools under a variety of conditions. Some studies exposed participants to the intervention

for only one short session; others made a Web site available to users over a specified period of time. Because of the differences in the tools, it is difficult to compare the effects of frequency, duration, and intensity across studies. There does appear to be a dose-response relationship in which those participants who showed the greatest use of a tool also showed the greatest benefit. No studies formally manipulated the frequency, duration, or intensity of use.

Types of Control Groups. The types of control groups used in these studies varied. Some control groups received no intervention. Others received treatment as usual, which might include in-person contact or informational brochures. It is possible that the positive effects of such comparisons in these studies are due to the use of the computer itself rather than the specific intervention.

Studies are beginning to appear that have control groups using alternative computer-based activities. For example, while the intervention group in the study by Jantz et al. used a program about nutrition, the control group interacted with a program on household budgeting (2002, TR#45). This type of comparison allows researchers to make a stronger case for attributing findings to the computer-based intervention itself rather than the novelty of the channel. Gustafson et al. points out that some of the benefits seen in their study may be due to loaning participants a computer, although they dispute this because their data showed significant actual use of the CHESS program (2001, TR#15). Further evidence is seen in the study by Barrera et al. in which the control group had computer access, but did not

show the same benefits as the intervention groups (2002, TR#2).

Capitalizing on Digital Technology for Research. Although evaluation of e-health tools shares many similarities with evaluation of other health-related media, some unique opportunities are specific to the use of digital technology. Research is beginning to capitalize on these attributes. For example, several studies used computer-based assessments that can streamline the data collection and entry process. Anecdotal evidence suggests that this approach can be a less threatening way of collecting data from populations with low literacy. Other studies have used online tracking systems that can help determine if participants actually used the programs and in which areas they spent their time. This type of process information can be very important in helping to determine what users find attractive and which program components are effective.

Final Thoughts

The research enterprise will need to be harnessed in a more coordinated and focused manner to ensure access and the availability of appropriate tools for people who want and need them. As noted in Chapter 1, "doing better" in the application of e-health tools to population health improvement means finding the best approaches to create tools that are "participatory, deeply meaningful, empathetic, empowering, interactive, personally relevant, contextually situated, credible, and convenient" (Neuhauser and Kreps, 2003). Meeting these requirements

will entail much greater attention to the use of participatory research methods and samples that reflect population diversity than demonstrated in the current body of research.

ENDNOTE: SEARCH TERMS

The following search terms were used in the search strategy for Chapter 3:

Health Information: A preprogrammed PubMed search was conducted under *Healthy People 2010* objective 11-4—Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site—using the following search terms (internet/standards[majr] AND (web OR website OR websites) AND (quality assurance OR quality control[mesh] OR confidentiality[mesh] OR privacy[mesh] OR ethics[mesh] OR health education/standards[mesh] NOT letter[pt] AND English[1a].

Behavior Change/Prevention: (Internet OR computer OR CD-ROM OR interactive multimedia) AND (behavior change OR health promotion OR prevention)

Online Communities: (Online OR Internet OR computer-mediated) AND (communities OR chat groups OR chat rooms OR listservs OR discussion groups OR support groups) AND health

Healthcare Tools: Personal electronic health record, personal electronic medical record, electronic messaging. Searches also were conducted for research related to specific healthcare tools as identified in the expert interviews.

Decision Support: Decision support, decision support tools, decision support AND online, decision aid

Disease Management: Disease management, disease management health tools, self-care tools, consumer health management tools