Online Behavior Change And Disease Management

A Research Dialogue

The National Cancer Institute
and the Robert Wood Johnson Foundation

August 2, 2001

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Executive Summary

Communications and behavioral scientists participated in a research dialogue on the facilitation of health behavior change using electronic health (e-health) interventions. The National Cancer Institute and The Robert Wood Johnson Foundation sponsored the dialogue.

Participants in the dialogue discussed:

1. Fundamental differences and similarities between conducting research of online versus "offline" interventions.

    Several issues that uniquely relate to e-health interventions were identified. Key issues were usability, tailoring of messages, and confidentiality of information collected. Participants also discussed the effective use of e-health technology and concluded that research is needed to increase the understanding of cognitive factors that influence the use and efficacy of e-health interventions.

2. Critical gaps in research methods for all phases of e-health intervention studies, including the need to standardize these methods.

    This discussion focused on gaps in understanding of appropriate designs for studying e-health interventions. Approaches should be developed and tested to ensure confidentiality as well as recruitment and participation of diverse and representative samples of users. Appropriate variables (e.g., exposure to technologies) and measures of these variables also must be identified, refined, and/or developed. Participants concluded that standardization and dissemination of methods and tools is a priority. Usability research may provide guidance regarding appropriate designs for e-health intervention studies.

3. Successful (and unsuccessful) approaches to and lessons learned in addressing barriers to research on e-health interventions for all phases of e-health intervention studies.

    Participants agreed that e-health intervention research should involve multiple approaches that are selected based on the anticipated use of the intervention over time and data from related e-health studies. Several elements of successful e-health intervention studies were identified for multiple phases of a study. Participants also noted several barriers they have encountered in their own e-health research (e.g., lack of familiarity with technology among target populations and Institutional Review Board requirements that are not conducive to e-health intervention research) as well as approaches that effectively overcame these barriers.

Participants emphasized the importance of translating findings, methods, and tools for e-health intervention research. Key driving and restraining forces for research into e-health behavior change and disease management were identified and are outlined in Table 1 on page 9.

Participants identified the following opportunities for improving e-health intervention research:

1. Use the Internet to disseminate evidence-based information/data internationally to researchers, clinicians, and patients on:
   a. Effective e-health interventions.
   b. Methods for assessing e-health interventions.
   c. Results of intervention assessments.
   d. New medical treatments and techniques.

2. Develop online interventions for continuing medical education of clinicians by providing feedback based on medical data that they input. This feedback will serve as an incentive for inputting medical record information and will help providers improve their performance.

3. Collaborate across a wide range of disciplines to establish methods and standards for e-health interventions and assessments. Involve the disciplines of health communications, computer science, marketing, library/ information science, information architecture and design, sociology, psychology, economics, and education.

4. Collaborate with the private sector to obtain data, methods and support for e-health intervention research.

5. Align studies of e-health interventions among underserved populations with the *Healthy People 2010* goal of increasing health literacy.

Background

A diverse group of communications experts and behavioral scientists met to participate in a research dialogue on facilitating health behavior changes through electronic health (e-health) interventions. The National Cancer Institute's (NCI) Division of Cancer Control and Population Sciences' Behavioral Research Program and The Robert Wood Johnson Foundation (RWJF) sponsored the meeting. NCI's online behavior research focuses on (1) technology to influence behaviors related to chronic disease, and (2) communication strategies to influence short- and long-term health cognitive, affective, and behavior changes.

The RWJF is interested in interactive health technologies, including (1) the development and implementation of online privacy and security standards, and (2) supporting and translating research on the effects of technology in chronic disease and health behavior.

The goal of the dialogue was to generate more frequent and rigorous research on e-health behavior change/disease management interventions. The dialogue focused on five questions:

1. What are the fundamental differences and similarities between researching online versus "offline" interventions?
    a. How are online interventions as opposed to "offline" interventions defined?
    b. How do online data collection activities compare with "offline" data collection activities?

2. What are the critical gaps in research methods on e-health interventions?

3. What are some successful approaches to and lessons learned in addressing barriers to researching e-health interventions? What are some unsuccessful approaches and lessons learned?
    a. Why did these approaches succeed or fail?
    b. What are some barriers to success and solutions to overcoming these barriers?

4. What are some topics or methods for which standardization/consensus would be useful (e.g., data collection instruments for specific behaviors or health conditions or standard measures of effect)?

5. What are priority areas and tools to address in the next 2 years that would promote more rigorous and more frequent research on e-health interventions?

Representatives from the NCI and RWJF emphasized that the dialogue should (1) identify research questions for online interventions, (2) determine how multilevel communication interventions can be used over time and how these interventions can be tailored and evaluated, (3) identify variables that should be examined in evaluating e-health interventions, and (4) suggest ways that existing research on e-health interventions can be translated into practice.

Differences and Similarities Between Studying Online Versus "Offline" Interventions

How are online interventions as opposed to "offline" interventions defined?

Participants agreed that interactivity refers to CD-ROM, Intranet, and Internet interventions. Complete interventions frequently involve a mixture of online and "offline" activities. One challenge will be to determine the balance of online and "offline" interventions that leads to the greatest behavior change. Some issues that uniquely apply to these types of interventions include:

- The need to address usability, navigation, and platform.

- The ability to tailor messages to the individual.

- Flexibility in time of use that makes the intervention more likely to be delivered during an individual user's "optimal matching period".

- An increased sense of privacy for some users or study subjects because of the lack of face-to-face contact and the ability to use e-health interventions at home.

- Decreased anonymity for some users or study subjects because of the sharing of information collected online and the ability of some parties to obtain "secure" information submitted via the Internet.

- Users cannot be sure who they are interacting with. Rework sentence

- The ability to deliver interactive information/interventions/assessments to large numbers of participants within a short period of time.

- The ability to deliver information/interventions/assessments to individuals in remote and sparsely populated locations.

- Audiences tend to browse information rather than read text in its entirety.

Effective use of technology

E-health interventions require that target audiences use and have access to the appropriate technology. These audiences also must be able to process and use the types of information that are delivered through these media. Research into cognitive processes and mechanisms that influence information processing should be identified and developed for various media formats. Research on the efficacy of e-health in general as well as specific interventions also must be compiled, gaps in that research identified, and studies conducted to fill those research gaps. Initial studies may identify and analyze existing sociodemographic data regarding who uses various technologies and e-health interventions, and who seeks health information online. Existing research on how individuals construct knowledge and where they go to obtain information also should be reviewed. Additional research may be needed to identify the audiences for various combinations of technologies, interventions, and information as well as to determine how various groups view and use these technologies/interventions/information (e.g., frequency of use, length of use, and credibility of information). Specifically, studies are needed that track Internet use among various population subgroups, examine target audiences' trust of e-

health information, and investigate the generalizability of e-health intervention research findings across different media modes.

Participants proposed the following research questions:

1. What is the impact of environment, systems and incentives on the use and efficacy of e-health interventions?

2. What factors lead to the adoption of technologies by various population groups?

3. How do users of e-health interventions customize their learning?

4. How does the use of online interventions differ from the use of "offline" interventions?

5. What factors influence the use of online interventions over time?

6. What is the optimal dose for different types of interventions?

7. What types of variables can most effectively be tailored?

8. What are the minimum and maximum number of variables that can be tailored effectively?

9. What are the most effective approaches for delivering online interventions?

10. What are the effects of patient/provider interactions on the use of e-health interventions?

Gaps in Research Methods on E-Health Interventions

Factors that impact the efficacy of "offline" evaluation research such as attrition, sample size, and selection and response biases also apply to assessments of e-health interventions. These factors need to be investigated in greater depth and addressed in e-health research designs to produce generalizable knowledge. The simple experimental designs frequently used in the study of traditional interventions may not be appropriate for the study of many types of e-health interventions. Appropriate comparison/control conditions also may differ for e-health intervention studies as opposed to traditional evaluations.

In general, investigators have less control over sampling, potential confounds, and other research design issues in e-health intervention studies, particularly if data are collected online. Methods are needed to identify, measure, and track potential covariates and confounds for e-health intervention studies over time and across space. Elements of e-health interventions must be deconstructed and examined with regard to their unique influence and interaction effects. For example, the effects of noise and signal variation should be studied and a metric for noise and signal variation needs to be developed.

Usability literature may provide some guidance regarding the appropriate design of evaluations for e-health interventions. Computer science and marketing experts also should be consulted to develop standards for designing e-health intervention studies.

Institutional Review Board approval

Potential risks and benefits of e-health intervention studies need to be communicated to Institutional Review Boards (IRBs). Issues of confidentiality are of particular importance to IRBs, but IRB members generally are not qualified to judge the degree of anonymity that a specific online survey will afford. Participants recommended that the sponsors of this meeting initiate transdisciplinary efforts to develop standard criteria for the review of e-health assessments. Individuals with expertise in the administration of online surveys, including security issues, also should serve on IRBs.

Sampling/recruitment

Participants expressed an interest in identifying effective online and "offline" methods for recruiting participants into e-health intervention studies. Currently, participants in most formal evaluations of e-health interventions are recruited through "offline" techniques that tend to produce higher recruitment and retention rates. The greatest challenge for online recruitment may be to establish credibility and ensure confidentiality. Investigators who use online surveys also need to clearly communicate the risks of participation to participants (e.g., what type of Internet use can be tracked). The benefits of participation also should be communicated to promote the use of e-health interventions.

Methods are needed for recruiting large samples that are representative of the general population to e-health studies. Health literacy and cultural biases tend to be amplified when respondents are self-selected. Underserved populations should be oversampled in more e-health intervention studies.

Selection criteria for studies of e-health interventions are complex. In addition to the eligibility criteria used in most "offline" intervention studies (e.g., sociodemographic characteristics and level of involvement), eligibility criteria for studies of e-health interventions may include access, technology skills, and media preferences. Appropriate inclusion and exclusion criteria should be investigated for both control and experimental groups in e-health intervention studies.

Data collection

Appropriate variables and measures of these variables must be identified, refined, and/or developed. Methods for determining exposure to online health information and how this information is used (particularly at the national level in a dynamic, real-time manner) would be particularly useful. Tools for collecting process data also are needed to effectively evaluate e-health interventions. Process data will provide critical information that allows investigators to better interpret outcome data and determine causation. One process measure that could be used is e-mail messages regarding user problems. Variables that measure the context of an intervention (e.g., time and location) need to be defined. Measures for collecting key outcome data also must be integrated and refined. In addition, improved methods of tracking behavior changes during and after interventions should be developed.

Participants emphasized the need to identify methods of effectively promoting the use of online data collection tools (for assessment and tracking purposes). Technologies and approaches that facilitate data collection (e.g., tracking systems and interactive devices that directly collect medical record data) and that increase the anonymity and security of information also must be identified. Information on these methods and tools should be compiled and disseminated to the e-health research community.

Other important gaps in available methods and tools for collecting data on e-health interventions include:

1. Procedures for conducting individualized studies of e-health interventions within the context of larger population-based studies.

2. Methods for evaluating online support groups.

3. Metrics that have been crossculturally validated.

Data analysis

Traditional statistical analysis approaches may not be appropriate for the analysis of data collected to assess e-health interventions. Appropriate approaches for analyzing data collected from e-health assessments must be investigated and new techniques developed.

Specific statistical analysis techniques have been developed to compensate for the lack of control groups or randomization in some e-health intervention research. Statistical simulations and permutation analyses should be developed for use in e-health intervention research.

Tools are available to track all online activities. The data produced by these tools may be useful but are difficult to analyze because they are so diverse. Participants recommended that researchers and technology experts collaborate to develop tools that can organize and analyze large amounts of tracking data collected online.

Topics or methods for which standardization/consensus would be useful

A critical gap that affects all stages of e-health intervention studies is the lack of standardized assessment methods and tools. A wide range of methods is used to evaluate e-health interventions, and these approaches need to be evaluated and standardized. Participants recommended that think tanks of experts across disciplines and organizations be formed to develop standards for e-health intervention research. They also recommended conducting a review of relevant literature and models used for this type of research across disciplines. Agencies that fund e-health intervention research should participate in these efforts. Other stakeholders, such as employers and insurers, also should be involved.

Standard study design guidelines

Standard e-health intervention design guidelines, including optimal location of design elements, need to be developed. Standard terminology and a standard list of variables with operational definitions should be included in these guidelines. For example, standard descriptors of user interactions (e.g., lurkers, frequent posters, etc.) can be compiled and disseminated. Unique standards are needed to address language, literacy, and cultural barriers for e-health interventions that target Spanish-speaking subpopulations. Recruitment criteria also must be carefully determined for studies that include Spanish-speakers.

Standard informed consent procedures also are needed for e-health intervention studies. The Health Care Finance Administration (now known as the Center for Medicare and Medicaid) requires that funded e-health intervention studies include a plan for disclosing how data will be used and destroyed. RWJF conducted a study of online data security requirements for 20 health care organizations. It found that privacy was a key issue, and some consensus has been reached across these organizations regarding the wording of privacy assurances.

Standard data collection procedures and tools

Lists of recommended process and outcome variables and tools for effectively measuring these variables should be compiled to guide e-health intervention researchers and increase comparability of data across studies. Standards also are needed for collecting and reporting data on usability of e-health interventions (e.g., time per question, number of keystrokes, etc.). Several mature metrics have been developed to test usability. These should be compiled and disseminated.

Standard protocols for integrating telephone and online surveys also need to be developed. The U.S. Bureau of Census may have some model protocols for dual modality assessment.

Standards for data analysis

Algorithm and message libraries need to be developed so that various algorithms and messages can be compared for their efficacy with different audiences, technologies, and intervention goals. Participants recommended that the sponsors of this meeting spearhead efforts to promote sharing algorithms and other analysis tools.

Approaches to and Lessons Learned in Addressing Barriers to Research on E-Health Interventions

Participants generally agreed that intervention research (as opposed to usability testing) should involve multiple approaches, including surveys of large and diverse samples, qualitative studies using smaller samples, laboratory and field experiments, and reviews of medical record data when appropriate. Intervention research also should consider the history behind interventions and the future direction of these interventions, as e-health interventions frequently are updated and adapted to the changing needs of users.

Study design

Elements of successful e-health intervention studies include:

1. In-depth assessment of the needs of target audiences prior to implementation and subsequent tailoring of interventions based on the needs identified.

2. Incremental development of an intervention through a process of formative evaluation and revision.

3. Provision of technology, staff, and training that allows participants to effectively use and evaluate an intervention.

4. Materials that are tailored to the culture and literacy of participants.

5. Incentives for use that are tailored to the target audience (e.g., survivors are more motivated by the opportunity to assist others; other audiences may be motivated by financial incentives).

6. Strategies for integrating interventions into clinical practice that are tailored to the environment of a specific clinic.

7. Designs that target multiple behaviors to measure the full impact of an intervention.

Recruitment

Successful recruitment approaches include:

1. Utilizing knowledge networks.

2. Using random-digit dialing to promote use and refine samples.

3. Recruiting through online support groups.

4. Integrating health messages into interactive games.

5. Recruiting through Internet service providers (e.g., America Online).

6. Using CD-ROMs and kiosks to reach audiences with limited access to the Internet.

7. Recruiting through small clinics rather than large medical centers.

8. Using a spokesperson to promote participation.

9. Promoting the use of specific e-health interventions among patients first, and then using patients to encourage use by providers.

10. Demonstrating the benefits to clinical workflow for healthcare providers.

Data collection

Successful data collection approaches include:

1. Brief, repeated probes (as opposed to extensive text surveys) to encourage completion of assessments and reduce missing data.

2. Feedback after every two or three questions on online surveys (care must be taken to ensure that feedback does not influence subsequent responses).

Data analysis

Successful data analysis methods include:

1. Propensity scores (developed by Harris Online), which allow data collected from nonrandom samples to be analyzed as data from random samples.

Barriers to Success and Solutions to Overcoming These Barriers

Participants provided several examples of barriers encountered in conducting e-health intervention studies. Some of these barriers and solutions implemented to overcome them are described in this section.

Study participants (particularly those with low income and education) failed to meet interactivity requirements. E-health interventions were supplemented with telephone calls and visits to a center.

Enrollment in a multisite study of cancer survivors and their families initially was low. Enrollment increased dramatically when 12 popular online message boards were used to recruit. Collaboration with a key player in the online support group community was necessary to use these message boards.

IRB concern about the "toxicity" of medical information initially blocked the implementation of one intervention. The efforts of several lawyers were required to overcome this barrier. Investigators obtained approval by responding in detail to each IRB concern about the study plan. This involved adding a requirement that all patients be connected with a provider as well as including procedures for triaging "upset" patients.

Inadequate participation of underserved ethnic minority groups in one study was resolved through a second-year supplement that allowed for oversampling of African-American and Asian participants. Recruitment techniques also were tailored to the target communities.

Fear of using a new technology and doubt about its utility were overcome by scheduling opportunities for target audiences to try a new intervention.

Clinicians often are reluctant to use e-health interventions and data collection tools. Compiling and disseminating information to clinicians about effective interventions, the theory behind these interventions, and their benefits to medical practice can minimize this reluctance.

Priority Areas and Tools To Promote More Rigorous and Frequent Research of E-Health Interventions

Meeting participants indicated that the translation and dissemination of findings, methods, and tools for e-health intervention research are critical. Standardization of methods and tools also must become a priority.

Participants identified key driving and restraining forces for research into e-health behavior change and disease management. These forces are listed in Table 1.

Table 1. Key Forces Driving E-Health Research

Driving Forces	Restraining Forces
Available funds	Lack of important stakeholder involvement and support of research
Cost savings from appropriate research	Lack of market for e-health interventions
Consumer demand/support for appropriate applications	Health delivery mechanisms/system
Appropriate regulations/legislation	Lack of standards/consensus
Movement toward population- and home-based health	Systems tend toward status quo
Lack of public awareness	Inadequacy of funding for research components
Demand for evidence to support use of technology by providers	Lack of options for interventions
Genome movement and resultant change in the health care paradigm toward genetic interventions (desire for evidence)	Technology infrastructure (e.g., bandwidth quality)
	Lack of collaboration between academic and private sectors
	Lack of researchers trained in e-health

Participants agreed that the forces they could most easily impact during the next 2 years are lack of standards/consensus, funding, and lack of commercial/academic collaboration. Participants also can increase the capacity of researchers to conduct e-health interventions and assessments through funded courses, scholarships, special programs, and similar activities. Policy also can be impacted during the next few years through dissemination of information on e-health intervention research to policymakers.

Opportunities

Participants identified the following opportunities for improving research on e-health interventions:

1. Use the Internet to disseminate evidence-based information/data internationally to researchers, clinicians, and patients on:
    a. Effective e-health interventions
        -   Methods for assessing e-health interventions.
        -   Results of intervention assessments.
        -   New medical treatments and techniques.

2. Develop online interventions for continuing medical education of clinicians by providing feedback based on medical data that they input. This feedback will serve as an incentive for inputting medical record information and will help providers improve their performance.

3. Collaborate across a wide range of disciplines to establish methods and standards for e-health interventions and assessments. Involve the disciplines of health communication, computer science, marketing, library/ information science, information architecture and design, sociology, psychology, economics, and education.

4. Collaborate with the private sector to obtain data, methods, and support for e-health intervention research.

5. Align studies of e-health interventions among underserved populations with the *Healthy People 2010* goal of increasing health literacy.

6. Examine behavior change models used by pharmaceutical companies.

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