Critical Issues in eHealth Research

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Introduction

Since the early 1950s, computer technologies have been used to gather, manage, and disseminate health information.[1] The development of microcomputer processing in the 1970s and its subsequent exponential increase in speed and memory, together with the proliferation of electronic network infrastructures to transmit large amounts of data (e.g., Internet, intranets, electronic medical records, telecommunication networks), have created ever-expanding opportunities to assess and deliver health information to individuals, groups, and populations. Computer technologies also have created extraordinary opportunities for real-time assessments of physiology (e.g., ambulatory heart rate monitoring, galvanic skin response), health behaviors (e.g., accelerometry), and self-reports (e.g., personal digital assistants [PDAs] that capture stress levels, diet, medication use) in the real world and to deliver individualized information in response.[2–3] In addition, interventionists can use the rapidly expanding palette of technologic capabilities to deliver evidence-based programs through the Internet in ways that are both individualized and cost-effective. There is evidence that behavior change programs delivered via the Internet, using data provided by users, can be highly effective.[4–7]

Yet, in spite of a surge of technologic capability, corresponding research and evaluation methodologies have not kept pace with the rapid evolution and proliferation of health information and communication technologies. Nor has the dissemination of effective eHealth interventions achieved the level of penetration that one might have hoped, given the number of people who now possess access to the Internet.

The Critical Issues in eHealth Research Symposium

In June 2005, the National Institutes of Health (NIH) convened a scientific conference, Critical Issues in eHealth Research, to provide an interdisciplinary forum to discuss major theoretical and methodologic issues in eHealth research. Prompted by the collective recognition that research methods should evolve along with advances in health information technologies, the conference convened government scientists, academic researchers from a variety of disciplines, computer engineers, patient advocates, and practitioners from the private and public sectors to examine the complex eHealth research issues related to the intersections among health science, communication technology, and research methodology. The conference was cosponsored by the Health e-Technologies Initiative (a national program office of the Robert Wood Johnson Foundation), and the following NIH divisions: National Cancer Institute, National Institute on Drug Abuse, National Institute of Mental Health, National Library of Medicine, Office of Behavioral and Social Sciences Research, and the Office of Disease Prevention.

Symposium participants identified and explored areas of congruence and controversy related to the development, evaluation, and dissemination of eHealth research and the products of this research. Scientists also discussed the interdisciplinary crossroads that lay the foundation for health applications of information and communication technologies, focusing particularly on the junctions among behavioral science, basic biomedical science, computer engineering, and the information sciences.

Use of the Internet in health research received extensive attention at the inaugural Critical Issues in eHealth Research conference for good reason. Public adoption of the Internet soared from a mere 15% of Americans in 1995 to an estimated 75% of Americans in 2006,[8] with more than 70 million American adults going online to use the Internet each day.[9] As more Americans are online, they rely on the Internet for important health information.[10,11] A 2005 report from the Pew Foundation estimates that 80% of Internet users have searched online for health information at some point in their lives,[12] and a large percentage of "health seekers" say that the resources they find on the web have a direct effect on the decisions they make about their health care and on their interactions with doctors.[13] Use of the Internet by Americans is just the tip of the iceberg, with projections for global use reflecting a true transformation in the ways in which governments address public health issues, businesses

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pursue economic opportunity, and individuals lead their lives.[14,15]

With respect to disease prevention and control, increased use of the Internet can facilitate information acquisition[11,16]; tailored dissemination of health information[5,15,17,18]; academic, commercial and governmental collaborations[18–21]; the adoption of healthy lifestyles, such as changes in diet, physical activity, weight, and smoking[4–7,15,17,22–24]; detection and treatment of disease[25–27]; and community outreach.[21,28–30]

Papers in This Issue

The papers in this supplement[31–41] highlight the major presentations at the 2005 Critical Issues in eHealth Research conference. They bring a unique perspective to the literature on key methodologic issues surrounding eHealth research and suggest new research methods for evaluation of eHealth applications. Diverse definitions of "eHealth" have been advanced, with little consensus.[42,43] For purposes of the conference, eHealth research was defined broadly as use of health information and communication technologies (e.g., Internet, personal digital assistants, digital cell phones, accelerometers, personalized/electronic health records, electronic medical records, CD-ROM) to assess, monitor, and improve health within a research context.

Ahern,[31] Hesse and Schneiderman,[32] and the invited commentary by Slack[33] provide historical perspectives about eHealth and user interactions with health information technologies. Ahern[31] outlines general research opportunities and challenges facing eHealth research and emphasizes the need to "promote adherence to the highest standards of research design and methodologic rigor to improve the overall quality of eHealth research." Ahern[31] also highlights the importance of theory in the development of eHealth research.

Hesse and Schneiderman[32] observe that potential errors in eHealth research and health care can be reduced and/or avoided and program effectiveness maximized by incorporating users' perspectives (how individuals interact with technologies and healthcare systems) into eHealth research and intervention design. They offer an ecologic conceptual framework that depicts the multilevel nature of the healthcare environment and suggest that eHealth programs consider the goals of users and health systems. Further, they highlight some of the gains that could be achieved in the development of user-centered eHealth interventions. Such approaches would transcend focus groups and other formative research methods traditionally used in health behavior research. Instead, the designs of interventions and tools would be guided by patients' and physicians' needs rather than by a priori or imposed models of need. Increasingly, the value of this approach is appreciated in the business sector.[44]

Couper[34] systematically addresses the specific (and thorny) research issues of sample representation in Internet surveys. This topic illustrates one of the key threats to the validity and generalizability of eHealth research findings. Dillman and Smyth[35] complement Couper's[34] discussion of Internet surveys by focusing on the relationship between visual design of Internet surveys and measurement error. Guidelines for Internet survey design are provided to increase standardization of surveys and reduce measurement error.

Lobach and Detmer[36] discuss the methodologic challenges of a separate eHealth research tradition, namely electronic health records (EHRs) (also referred to as electronic medical records). In contrast to the Internet, EHRs have not been as readily adopted by medical practices and health systems as their apparent utility might lead us to expect. Unique methodologic challenges face evaluation of EHRs. Lobach and Detmer[36] observe that traditional randomized controlled research designs may not be feasible in research using EHRs, and they discuss alternative research designs. Similar to the view put forth by Hesse and Schneiderman,[32] Lobach and Detmer[36] suggest that consideration of the multiple levels of the healthcare system and the human–computer interface are vital to obtain reliable and valid health information. They also echo the recommendation of Ahern[31] to incorporate the research question (i.e., theory) into the design of eHealth studies, in this case, using EHR evaluation.

Collins et al.[37] offer two novel methods for developing and evaluating eHealth interventions. The methods proposed, based on randomized experiments, provide researchers with ways to maximize and tailor behavioral interventions using the richness of electronic data. Moreover, the methods Collins et al.[37] propose, which parallel trends in the evaluation of clinical trials, are aimed at getting research answers more expeditiously and efficiently. These innovative methods take advantage of the extensive data that can readily be collected in eHealth research.

Glasgow[38] extends the discussion of eHealth research beyond assessment and intervention to research dissemination. The concept of practical eHealth trials is offered in which study representation, research settings, alternative comparison groups, and relevant stakeholder outcomes all are considered in an effort to maximize balance between internal validity and generalizability of eHealth study results. Glasgow[38] provides research recommendations and a discussion about the RE-AIM dissemination model as potential strategies by which to extend eHealth research into real-world practice. Consideration of how to disseminate effective eHealth interventions is critical since it is clear from other health domains that dissemination usually falls short of its potential. Because of the possibility of scaling eHealth interventions for dissemination to many millions of people, it is critical that we understand how to achieve dissemination of effective eHealth interventions that is appropriate and efficacious, not just pervasive.

Common themes among the various papers in this special issue include the importance of examining sample representation, tailoring information according to users' needs and characteristics, considering multiple levels of analyses (e.g., individual, dyad, environment, policy, systems), and using theoretical models/ research questions to guide the development of study designs. In addition, eHealth research among at-risk and under-served populations, health disparities, digital divide, privacy/informed consent, and economic issues were discussed and debated at the 2005 Critical Issues in eHealth Research conference. While a full discussion of these topics is beyond the scope of this paper, invited commentaries by Curry[39] and Viswanath and Kreuter[40] touch on several of the critical issues in these areas.

Conclusion

eHealth research is at an early stage of development. The 2005 Critical Issues in eHealth Research conference and subsequent papers in this special issue represent notable benchmarks that future eHealth research studies can reference. eHealth research and the information collected from such research are complex. If designed, developed, and employed optimally, eHealth applications have the potential to bridge health disparities, facilitate analysis of population-level data to enable tailoring of healthcare delivery, and speed the translation of discoveries into practice—advances that parallel revolutionary developments in biomedical science in the form of molecular targeting of drugs and the mapping of the human genome.

Like other biomedical advances, eHealth applications have the potential for both benefits and harms. The latter include the potential to endanger patient privacy, increase health disparities, lead patients away from effective treatments, and widen the digital divide. The latent power of this burgeoning medium requires researchers from different sectors (industry, government, and academia) to collaborate on how best to harness the technical capabilities of emerging information technologies to support the social and cultural realities in which people work and live, while enhancing the systems ability to address the health needs of individuals. Only in this way will research methodologies emerge that effectively support, guide, and direct these applications. In a global environment in which national boundaries no longer constrain information flow, it behooves us to use all the tools at our command to improve health across the world. Increasingly, eHealth tools are an important part of the arsenal for improving population health. Finally, over the years, considerable concern has been raised about the possibility that computers will eclipse people. A strong message delivered by multiple speakers at the conference was about the centrality of the human interface, perhaps best summarized by Hesse and Schneiderman[32]: "Patients and their families must be engineered into the system as a first line of defense against potential errors, not the last."

We should also heed the caution articulated by Crounse[41] in his invited commentary:

> [A]ll too often our methodology falls back on that which we know and have always done before . . . . But we must . . . not dig in our heels, resist change and continue to conduct business as we've always done so before just because it suits our comfort level. Others around the world will not indulge in, or tolerate that luxury.

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