The Future of eHealth Research: A Qualitative Study

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Health e-Technologies Initiative
A National Program Office of The Robert Wood Johnson Foundation
Health e-Technologies Initiative

- $10.3 million national program of The Robert Wood Johnson Foundation
- 5-year initiative, began in February 2002
- Supports evaluation research on eHealth applications for health behavior change and chronic disease management
Purpose

• To assess the state of the field of eHealth and its future directions, especially for health behavior change and chronic disease management

• To guide the formulation of the research agenda for the Health e-Technologies Initiative
Areas of Focus

- Application development
- Research methods and challenges
- Perspectives on quality, effectiveness and value
- Potential impact
- Traditionally underserved populations
- Cost-effectiveness
Methods

- 38 semi-structured interviews with opinion leaders (stakeholders) in eHealth
- Interviews were audio taped and transcribed
- Coded and analyzed using qualitative research methods (N*Vivo software)
Stakeholders

- Established developers/researchers of eHealth applications
- Projects/programs that have implemented eHealth applications
- Health plan representatives
- Technology and health care futurists
- Opinion leaders in Information Technology
- Physician organizations/provider groups
- Purchasers (public/private coalitions, larger employers)
- Consumer groups
- Data collectors
- Pharmaceutical industry leaders
Theme 1:
Consensus and Standardization

- Coordinated, rigorous effort needed to define and integrate the field
- Universal concern with lack of standardized measures
- Criteria needed for:
  - Identifying quality information
  - Comparing findings
  - Building upon results to move eHealth forward
Areas of Emphasis, by sector
“...the most critical challenge is not working in isolation and certainly understanding what other people are doing in this arena. We...don’t want to reinvent the wheel.”

- eHealth Opinion Leader
Theme 2: Evaluation Approaches

- **Outcome Measures**
  - Poorly defined
  - Not validated for online use
- **Process Measures**
  - Distinguishing between usage behaviors
  - Explain threats to internal validity
  - Related to relevance of outcome measures
- **Tensions in evaluation-development cycle**
- **Relevance of eHealth research environment to applications already in use in healthcare and commercial industry**
“I would say all the steps along the journey... from identification of person with the disease, to watching out for regression to the mean, for looking for a matched patient population, for being able to accurately portray the decrease in utilization to making sure that the economic impact can really be documented and isn’t just in increase in opportunity cost, there’s just a host of problems that most of the research is still facing.”

- eHealth Developer/Researcher
Theme 3: Perspectives on Quality, Value & Future Potential

- Efficacy and usability are considered crucial
- Stakeholders were concerned that end users (and some purchasers) are not as focused on the need for demonstrated effectiveness
- Changing role of information in healthcare
- Public health perspective
“[I]t’s like the Wild West out there. There are selected good resources. Connecting patients with the right resources is a huge challenge.”

- Health Care Provider

“The things that tend to lead people to trust a system are not the kinds of things that probably indicate the quality of a system... people tend to believe in stuff that’s flashy, rather than in-depth.”

- eHealth Opinion Leader
Bridging the Digital Divide

Highest growth in eHealth use is among users with low income and low education levels.

Technology is increasingly becoming ubiquitous and affordable.

Widening the Digital Divide

eHealth is developed from a user perspective, but not all users will find culturally competent applications. Advanced eHealth programs may not be compatible with older, more affordable computers and other technologies.

Access is Key

Utilization is not the problem. Technology has the capacity to surmount linguistic, literacy, and cultural barriers.

Theme 4: Health Disparities
"I don’t think we’re lessening the divide because the underserved are also underserved as far as their access and time to go on the web."

- Implementer of eHealth Applications

"The people who are most likely to benefit from these systems right now are the people who are most underserved because they don’t have any other resources to go to."

- eHealth Developer/Researcher
Conclusions

• Traditionally underserved populations will particularly benefit if access to technology is ensured.

• Demonstrating outcomes essential to establishing eHealth quality and effectiveness. Process measures crucial to informing validity of results. Improvements of existing measures of process and outcome are needed.

• Building infrastructure to support widespread dissemination is crucial. Future challenges for health systems are to align technologies with workflow and reimbursement incentives, ensure technical interoperability, and enhance consistency of care.