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Using health information technology to engage communities in health, education, and research

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Abstract

The August 2011 Clinical & Translational Science Awards (CTSA) conference *Using IT to Improve Community Health: How Health Care Reform Supports Innovation*, convened four “think tank” sessions. Thirty individuals, representing various perspectives on community engagement, attended the *Health Information Technology (HIT) as a Resource to Improve Community Health and Education* session, which focused on using HIT to improve patient health, education, and research involvement. Participants discussed a range of topics using a semi-structured format. This article describes themes and lessons that emerged from that session, with a particular focus on using HIT to engage communities in order to improve health and reduce health disparities in populations.

Using HIT to Engage Communities

The Internet has the potential to empower individuals to facilitate self-management of their own health (1). Although many “think tank” session attendees at the Clinical &

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Translational Science Awards (CTSA) conference *Using IT to Improve Community Health: How Health Care Reform Supports Innovation* used technology to advance personal education or research goals, most expressed interest in additional opportunities to engage a variety of audiences, including communities, teachers, students, non-English speakers, and low-literacy individuals, to further health education and research. Table 1 compiles knowledge pooled among the session participants regarding applications of HIT, including its current usage by session participants to engage with communities.

Attendees at the think tank session *Health Information Technology (HIT) as a Resource to Improve Community Health and Education* cited examples of existing technologies that link underrepresented or underserved minorities with resources that aim to bridge health disparities and gaps in health care and clinical research (2). HIT enables organizations to provide targeted messaging to users based on their health needs, and to manage outreach to a larger population than the individual level or those who are already receiving services. Information technologies also have potential to increase research participation while simultaneously providing health education materials and resources (1).. For example, some families use cell phone technology to gather information from the Internet because they do not have a computer in the home. Participants in the session agreed that approaches to integrate informatics with health messaging could enable users to better manage their own health outcomes. For example, such approaches could enable the delivery of tailored resources and self-selected information that is either targeted towards individuals with health concerns or which support health and prevention (Table 1; 3–6).

Partnership Considerations

Participants readily agreed that data sharing and technology are ways to provide information to both individuals and populations. Several modes of communication can be applied to developing effective platforms that engage individuals and communities in self-directed health management. Data in graphical formats provide visual representations that may be better received than text alone. Individuals comfortable using technology, are often willing to take a hands-on approach to explore data and share this information with their families. Older audiences not familiar with technology are also responsive to HIT, especially when involved in the development process of tools that support health maintenance (3). User-centered approaches help researchers determine the appropriateness of the message and if the information is reaching the intended target audience.

Although community-based organizations and the people they serve are assets to community-engaged research, there is often insufficient recognition of this inherent expertise. Community partners are often not fully integrated throughout the research process. It is important to remember the bidirectional nature of community engagement and to include community members with a range of knowledge and experience. Technological resources for maintaining open communication channels between researchers and community members—for example, Skype, Facebook—are readily available to those with both computers and hand held devices (Table 1; 7–10) and enable rapid communication at minimal cost, especially with long-distance partnerships. Using technology as a communication strategy could facilitate partnerships and sharing of information to reduce disparities.

Current Limitations of HIT and Opportunities for Expansion

Several limitations exist as a result of the laws regulating HIT and the validity of the data obtained from multiple sources (11). Despite major advances in communication technology, such as community health data sharing and social networking sites, the session group noted that laws and regulations governing health education and research have not kept pace

(12,13). Concerns around privacy regulations, especially the Health Information Portability and Accountability Act (HIPAA) for personal and community health data as well as with Institutional Review Board (IRB) oversight regarding the use of social networking for research purposes and disseminating health education information were expressed. Advocating policy changes for social networking in the research approval process could increase the pace of laws and governing regulations.

The other concern voiced during the session pertained to the validity of data obtained from multiple sources. Several participants expressed concern that such multisource data often differ in format, labeling, or collection method. This could be overcome by developing more cohesive and integrated systems that provide meaningful and useful data to both community members and researchers alike.

Interfacing HIT with Communities

New users wanting to incorporate HIT into their work should remember that community priorities should drive the technology, rather than using technology simply because it is available. A user-centered, iterative design process can be applied, which allows maximum participation by all who have a vested interest in improved health status. For instance, developing and distributing technology applications is not a shortcut to building rapport with individuals within a community. HIT resources should not solely focus on developing and delivering “apps,” even if they seem useful, relevant, and user-centered. It is important for community members to be involved in the development and evaluation processes of new technologies.

Evaluating HIT Efforts

Evaluating the effects of HIT on a community can be a challenge. Evaluation needs to occur at multiple levels: both individual and organization, and within the larger community context. Researchers and those interested in using HIT need to find ways in which data collection and analysis ultimately provides the individual with useful information. Using IT to assess the infrastructure of a partnership between, either in a single community or in multiple locations, may be helpful, as it provides a rapid method to determine if all those involved in an effort are on “on the same page”, resulting in a consensus on priorities. Despite the challenges expressed by individuals at the onset of the section, there was strong agreement that multiple opportunities exist for using technology in the evaluation process (14).

Technology Outlook

The Internet, technology, and information continue to grow at a startling pace. There are eloquent examples of HIT being used to improve health and to engage communities (Table 1). Despite this growth, the group expressed continuing concern that researchers can often forget that interactive technology is not the same as engaging community members. Community engagement, with or without HIT, requires ongoing bidirectional communication between community members and their health care providers to facilitate trust and equity in the process. An opportunity exists for researchers and community members alike to use technology in a thoughtful and respectful way to promote health. Such a communication framework could be useful toward improving the health of individuals and to reducing health disparities worldwide.

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Table 1

Types of health information technology and applications used by session participants to engage communities in research and education. Participants of the session (n=30) indicated which approaches they were currently using through a show of hands, which were tabulated by the session organizer. The education and research goals for using these HIT approaches were also tabulated

Examples of HIT	Uses	Current Users in Think Tank session* [n – individuals (%total users)]
Surveys and data collection tools (4,5)	Tailored educational feedback based on results; improving interactions between community health workers and community members; collecting data from large populations; collaborations from multiple organizations on survey design and instruments.	7 (23%)
Electronic health records and personal health records (patient registries, Web portals(6), community clinic data (3)	Access to health records; community surveillance; increase statistical power of research studies; creation of patient support networks; tailored education to patients	7 (23%)
Geographic Information System (GIS), Geomapping (15–21), and Data in Graphical Formats (e.g. Tinkerplots)	Distribution of resources, networks and/or relationships displayed across local, regional statewide areas; surveillance of community health issues and health disparities; rapid visualization of data trends	6 (20%)
Social media and networking (7–10) (Facebook, Twitter, Skype, instant messaging, texting)	Reminders of health meetings, classes, appointments, or taking medication; delivering inspirational or coaching messages; interacting with community health workers; delivery of health/ public health information	5 (17%)
Other [clinical trial recruitment registries (22, 23), websites and web portals (2, 6), online training workshops and webinars (24), biolibraries and biobanks (genomic, tissue, and data) (25)]	Provide access to individuals interested in future research studies; providing education and patient information related to health issues and diseases; train individuals in research and education; increase capacity for future research.	4 (13%)
How are these being applied to community engagement efforts?		
Research goals		7 (23%)
Education goals (2)		4 (13%)
Both (3–5)		6 (20%)

* Participants could respond to multiple categories.