Participatory Design and Artificial Intelligence: Strategies to Improve Health Communication for Diverse Audiences

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Abstract

A major public health challenge is to develop large-scale health communication interventions that are successful with diverse and vulnerable audiences. Participatory design approaches are critical to create communication programs that are relevant to people's literacy, language, culture, access and functional needs. Further, there are powerful synergies in linking participatory design and artificial intelligence methods. This paper focuses on traditional weaknesses of health communication, and participatory design strategies and models that can be used by developers, researchers and health practitioners.

Why health communication matters

As annual US health care costs escalate to over $2.3 billion (16% of the Gross Domestic Product), there is increasing pressure to improve health and reduce demands on the health care system (CMS 2010). One half of deaths each year have been attributed to preventable behavioral and social factors (McGinnis & Foege 1993). A US Institute of Medicine (2003) report, provided estimates that early detection screening could reduce mortality rates from various cancers from 25 to 80%. Unfortunately, public health and medical efforts have proven woefully inadequate to reach US population health goals (USDHHS 2000). Rates of obesity and diabetes continue to skyrocket (USDHHS 2008a; USDHHS 2008b). Equally distressing are the ever-widening health disparities that result in a disproportionate burden of disease among minority groups in our society (Kreps 2006).

Health communication, "the central social process in the provision of health care delivery and the promotion of public health" (Kreps 1988), has been a primary strategy to improve people's health. This strategy has historically focused on disseminating evidence-based messages from experts to the public in the hope of motivating them to adopt healthy behaviors and use health care effectively. However, there are many other viable channels for disseminating health information to different audiences. Clearly, there is a major gap between our well-intentioned communication actions and what people actually do.

Health communication problems

Although one-way, generic messages from experts to the public ("Exercise 30 minutes a day;" "Eat 5 fruits and vegetables a day") are based on solid scientific research, they have often shown disappointing outcomes. Health communication models and approaches have over-emphasized individual risks and rational decision-making (Neuhauser & Kreps 2003). Research during the past half century is helping us understand that people's health decisions are greatly influenced by dynamic and complex social contexts. Our view is: "We experts have messages to send, but people have lives to live, and rarely do we bridge that gap." Newer "socio-ecological" models take into consideration how socio-cultural, institutional and environmental factors at multiple levels affect people's behaviors (Stokols 2000). Such models also draw on important findings of social epidemiological research showing that people's sense of control over life conditions may be the best predictor of their health (Syme 1991).

Recommendations to do better

Radical changes to thinking about health communication have prompted key recommendations to improve our efforts (Neuhauser & Kreps 2010):

Strengthen health behavior models

Socio-ecological models are providing important guidance to improve health communication through attention to multiple social contexts. However, more work is needed to define *how* people dynamically interact with health decisions and actions within and among these contexts. The fields of social semiotics, cybernetics, informatics, artificial intelligence and others are making significant contributions to our understanding about how the "receiver" (rather than the expert "sender") perceives and interacts with health information to take more control over their health. For example, social semiotic models focus on gaining a deep understanding of how people react to messages in their social settings. Social cybernetic frameworks posit how people use information to achieve goals within their social systems.

Design communication that is more personal and contextual

Given the ever-widening health disparities, generic health communication has clearly failed to meet at-risk groups' needs for information that is relevant to their literacy level, language, culture, access and functional needs. For example, although the average US adult is estimated to read at an 8th grade level, most health information is written at a 10th grade or college level. An estimated 90 million American adults lack the skills to understand health communication they receive (Kutner, Greenberg & Baer 2005). Contextualizing information to people's life situations can help them better navigate the health care system and find social support to change entrenched health behaviors. Likewise, it's essential to help people identify specific steps to take action (such as how to customize a personal exercise plan into their schedule).

Enhance the interactivity of communication

The classic approach of telling people what to do to improve their health is often off-putting, disempowering and ineffective (Neuhauser & Kreps 2003). Change is "transactional": people become aware of advice (get screened for cancer), engage in a process to internalize a message (this is important to me), understand the steps make a change (navigate the health care system), weigh the benefits (early detection) and costs (time, expense, fear of findings) of adopting the behavior, make a decision, and finally take action to carry out and maintain the behavior. Therefore, people not only need health information that is relevant to their personal situation and social contexts, but also need support during the decision process and carrying out a behavior change. Successful communication enables and motivates people to "take control" of that process. Increasingly, research shows that outcomes are better with interactive, as compared to one-way, communication. The more people participate in, and "drive" the communication process the more likely they are to make healthy changes.

Create communication with personal impact and population reach

The goal of public health is to improve health on a large-scale. Traditionally, the most effective health communication approaches have been those that are interpersonal—for example face-to-face counseling between patients and physicians. However, interpersonal communication is also expensive and increasingly difficult to accommodate in today's health care system. Mass media approaches (brochures, TV, radio, etc.) are less costly and have broader reach, but often show weak health effects. When mass media communication is designed to be more relevant to people's needs, outcomes are improved (Neuhauser et al. 2009). E-health communication is a revolutionary development and is thought to have the greatest overall potential to improve the outcomes of health communication at a population level by combining interpersonal and digitally mediated communication.

The promise of e-health communication

The emergence of "e-health" communication—communication that is mediated by the Internet or other digital technologies—offers unprecedented opportunities to overcome many of the weaknesses of traditional health communication and extend more effective communication to many people at low-cost. E-health features include the capacity to craft communication to an individual's specific demographic and health characteristics or personal information preferences ("mass customization," or "tailoring"). Computer-automated telephone, e-mail, or SMS text reminders, online health communities, in-home biometric devices, interactive health games, and an ever-increasing array of new applications, are making it possible to create highly personal, socially contextual and interactive communication. If, as epidemiological research suggests, "control" is the factor most predictive of people's health, e-health communication offers the most opportunities for people to take that control.

Nearly three decades of e-health communication research show overall positive outcomes among diverse populations and across many health conditions (Neuhauser & Kreps 2010; Neuhauser & Kreps 2003). However, important challenges still threaten the potential of e-health strategies to improve people's health on a large scale and reduce health disparities. Although Internet and other digital media usage is growing rapidly, many people with barriers related to literacy, language, disability, or income, lack effective access. Further, the results of e-health communication interventions show uneven outcomes. When developers do not take advantage of the potential of these new media to be deeply meaningful and useful to the intended beneficiaries, the results are sometimes as disappointing as they have been in the past.

The power of participatory design

A major flaw in the development and implementation of health communication approaches has been that the intended beneficiaries are usually not closely involved. The gap between "experts" and "the public" (or "sender" and "receiver") is often too great for our interventions to be successful. Fortunately, we have learned a great deal about how participatory design techniques can improve health communication (Hesse & Shneiderman 2007).

Involvement of users in the design and implementation of interventions has long been advocated by major public health institutions (WHO 1981), but it has taken time for this approach to become widespread. The participatory design movement originated in the fields of engineering, architecture and urban planning (see Neuhauser 2001). Participatory design has been defined as "an approach to the assessment, design and development of technological and organizational systems that places a premium on the active involvement of …potential or current users in design and decision-making processes" (CPSR 2000).

During the past two decades, "user-centered" design processes have become central to the design of computing systems and informatics (Schuler & Namioka 1993), but are still far from the norm in health communication.

Participatory design, artificial intelligence and cybernetics

McCarthy (2010) defines artificial intelligence (AI) as "the science and engineering of intelligent machines, especially computer programs" and as the "computational part of the ability to achieve goals in the world." From its inception in the mid-1950s, AI has emphasized participatory design to simulate capacities of human intelligence, and to ensure that people can effectively use the machines and their applications (Gil 1989; Russell & Norvig 2009). The field of AI is synergistic with that of cybernetics: AI focuses on design and implementation of machines to accomplish goals; cybernetics focuses on describing the regulation of technical, social and other systems towards goals (see: Pangaro 2010; Winograd & Flores 1986; Wiener 1948).

In both fields, the use of participatory design techniques is highly sophisticated and can be a rich source of guidance for developing intelligent interactive health communication programs. Likewise, public health research can inform AI developers and cyberneticians about fine distinctions among sub-groups in society who could benefit from better functional access to computing systems and their adoption.

Examples of participatory design in health communication

The following examples illustrate two projects that incorporate principles of participatory design, AI, and cybernetics to create more effective health communication programs by and for diverse, underserved populations.

Mass media materials for Medicaid beneficiaries

The Medi-Cal Access Project began in 2006 to address the problem that many of the million seniors and people with disabilities (SPD) on Medicaid in California had poor understanding of how to choose and navigate health care systems. Available materials were written at a graduate school level. The Health Research for Action (HRA) center at the School of Public Health, University of California, Berkeley, used a participatory process with SPD beneficiaries to co-design a guidebook with them (see Neuhauser et al. 2009 for a detailed description).

Participatory methods included: 1) establishment of a steering committee of diverse SPD beneficiaries, service providers, policy-makers and researchers; 2) focus groups and in-depth interviews with SPD beneficiaries and service providers to elicit key communication issues and concerns; 3) initial drafting by HRA staff of the guidebook, using "plain language" principles; 4) five iterative rounds of usability testing and focus groups to test prototype content (including readability testing to assure that content did not exceed a 6-7th grade level); 4) concurrent planning of statewide distribution with SPD beneficiaries and multiple state and community stakeholders; 5) guidebook adaptation into 13 languages; and 6) distribution to beneficiaries.

The communication intervention was evaluated with pre-post telephone surveys, focus groups and interviews with beneficiaries and providers and through a randomized-controlled trial with beneficiaries in three counties (Neuhauser et al. 2009; Kurtovich et al. 2010) Studies documented the complexity of the participatory techniques and SPD beneficiaries' and providers' significant contributions to improving all aspects of the guidebook's content, format and usability. The resulting resource was awarded the Institute for Healthcare Advancement's 2008 first place Health Literacy award for Published Materials. Quantitative results showed marked improvements in beneficiaries' satisfaction, knowledge gains, and capacities to make health care choices.

CrohnologyMD

Crohn's is an auto-immune disease that causes serious gastro-intestinal and other problems that are extremely hard to accurately diagnose and clinically manage. The ChronologyMD project, initiated in 2010 with funding from the Robert Wood Johnson Foundation, is a partnership of the Healthy Communities Foundation, HRA, and the University of California, San Francisco. The project is using participatory design and AI methods to understand more specifically how patients experience Crohn's on a daily basis via "observations of daily living," ("ODLs"), what clinicians need to know from patients, and how to create a shared communication system for better decision-making. Methods include 1) focus groups and in-depth interviews with patients and with clinicians to define key knowledge variables that are personally and clinically relevant; 2) AI methods to create decision algorithms and human-computer interfaces that capture and display important data useful to patients at home and to clinicians in medical settings; 3) iterative usability testing with patients and clinicians; and 4) iterative observations of the system in clinical settings. Results are expected in 2012.

Discussion and Lessons Learned

Participatory design techniques have emerged as a critical way to overcome the weaknesses of traditional health communication approaches. Such techniques enable developers and users to co-create communication that is highly relevant to people's personal and social contexts, and that is motivating and actionable. Although these techniques are not yet widespread, two decades of research shows positive outcomes from this approach. Combining participatory design, AI methods, and cybernetic guidance is an especially promising strategy to improve health communication for diverse and vulnerable populations. Achieving this vision is challenging: more research is needed to refine participatory design techniques, demonstrate their added value, and promote their adoption among developers, researchers, practitioners and funders.

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