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Social Participation in Health 2.0

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Abstract

Computer scientists are working with biomedical researchers, policy specialists, and medical practitioners to usher in a new era in healthcare. A recently convened panel of experts considered various research opportunities for technology-mediated social participation in Health 2.0.

Keywords

Information technology; Internet/Web; eHealth; Health 2.0; Technology-mediated social participation

In 2006, leaders of the UK's National Health Service made a prescient observation: to extend citizens' lives while preventing a budget meltdown, the government must foster a patient-led revolution in healthcare. "Patient and public involvement are at the centre of the modernization of the NHS in England," they explained. "Creating a patient-led service means enabling patients both as citizens and as consumers to become actively engaged in shaping, planning, and monitoring the health services they use."¹

Across the Atlantic, leaders in the computing industry observed that the fundamental changes inherent in the Web 2.0 movement—changes that emphasize participation, shared data, and collective intelligence²—might enable a similar healthcare revolution in the US. Health 2.0, as some call it,³ would let Americans be more proactive in relation to their own health and healthcare—even to the point of assisting in the acceleration of biomedical scientific discovery, lobbying for healthier laws and environments, and engaging more directly in medical decision making.

Tensions exist, however, in discussions of how to deploy Health 2.0 technologies in ways that increase benefits without jeopardizing gains made in the past century to protect the population's health and safety.⁴ Public health officials have repeatedly expressed concerns that some information—such as the personalized risk profiles offered by genomic sequencing companies—may overwhelm or even mislead individuals struggling to make life-and-death decisions in the context of nascent or unsettled science.⁵ Meanwhile, medical

The good news is that evidence from the psychological and organizational sciences is beginning to inform the debate.⁶ Computer scientists are beginning to work in tandem with biomedical researchers, policy specialists, and medical practitioners to create a blueprint for how to use technology-mediated social participation (TMSP) to usher in a new era in healthcare.

A STRATEGIC INVESTMENT IN HEALTH IT

What are the opportunities for investing in participative health and healthcare technologies? And where do these opportunities lie within a larger strategic health plan for the US?

To answer these questions, it is useful to consider a report released by the US Department of Health and Human Services (HHS) National Committee on Vital and Health Statistics (NCVHS) in the wake of the 9/11 terrorist attacks. "Information for Health: A Strategy for Building the National Health Information Infrastructure"

(http://aspe.hhs.gov/sp/NHII/Documents/NHIIReport2001) called for putting an end to fragmentation within health-related data systems and urged the creation of "an effective, comprehensive health information infrastructure that links all health decision-makers, including the public."

The NCVHS report outlined three essential spheres of participation in the 21st-century national health agenda: a *personal* sphere, made up of individual citizens looking to inform vital decisions about their own health and that of their loved ones; a *clinical* sphere, made up of practitioners and biomedical scientists collaborating on individual cases to seek the best treatment; and a *population* sphere, made up of public health officials and communities aiming to implement the most effective and equitable policies. The authors indicated that a computer-based infrastructure was needed to ensure the seamless flow of information from one sphere to the next, with distributed network technologies connecting relevant stakeholders. Because integrating the existing biomedical informatics structures would be especially challenging, they called for the creation of a national office dedicated to coordinating IT development within and between hospitals.

In a continuing effort to modernize the US healthcare system, President Bush in his 2004 State of the Union message called for connecting the majority of Americans to electronic health records (EHRs) by 2014. The same year, by executive order, HHS created the Office of the National Coordinator for Health Information Technology to oversee national health IT efforts.

By 2009, however, it had become obvious that the movement to diffuse EHRs across the population was lagging. Congress responded by passing the Health Information Technology for Economic and Clinical Health (HITECH) Act as part of the "stimulus bill," the American Recovery and Reinvestment Act. HITECH aims to stimulate adoption of EHRs through monetary incentives for the "meaningful use" of health IT in the short run, and to penalize lack of meaningful use (at least for Medicare providers) in the long run. The definition of meaningful use has been a subject of debate, but discussions have been influenced by a 2009 report from the National Research Council calling for greater "cognitive support for physicians, patients, and their families" and a greater emphasis not on technology but on medical outcomes.⁷

Although discussions about a national health information infrastructure have often been limited to EHRs, the NCVHS report's emphasis on improving and integrating personal, clinical, and population health information remains the blueprint for the future. HHS remains committed to the notion that patients should be empowered with tools to pursue the best health strategies for themselves and their families, while interacting with a responsive system distributed across areas of primary care and specialization. It also understands that these participative efforts will only yield results at the macro level if individual communities cooperate by altering their policies and improving incentives.

In that context, a panel of experts convened in April 2010 with the support of the National Science Foundation to consider the research opportunities within each sphere of participation identified by the NCVHS, as Figure 1 shows. For each opportunity, the panel generated a series of questions that should drive development and utilization of TMSP systems.

PERSONAL HEALTH INFORMATION

In 2001, when the NCVHS report was released, predictions were mixed as to whether patients would have the capacity to participate fully in the online flow of medical information as proposed. In fact, around the same time the American Medical Association offered a "New Year's resolution" for patients "not to go online to look for medical information before meeting with their physicians." Assuming the need for a protectionist stance, regulators went out of their way to insulate individuals' medical information to the point of dampening collective research efforts through restrictive interpretations of privacy clauses.⁸ Patients were often dissuaded from online health investigations and discussions, with epithets such as "cyberchondria" suggesting that too much patient engagement might be a bad thing.

In spite of these warnings, the US population was not inhibited in its use of the Internet to obtain information on health conditions, drugs, exercise and diet regimens, doctors and hospitals, insurance providers, and a host of other health-related topics. Many lay people proved to be much more adept at finding, evaluating, applying, and synthesizing health information than the medical establishment assumed, with countless examples of "e-patients" and patient communities educating medical professionals as opposed to the other way around (for example, see http://e-patients.net).

Patients also found strength in numbers. Early support communities such as the e-mail lists at the Association of Cancer Online Resources (www.acor.org) removed the sense of isolation many felt while struggling with the realities of a diagnosed ailment. More sophisticated social networking sites such as PatientsLikeMe (www.patientslikeme.com) have since augmented these early online communities. Founded by two brothers who sought to create a participative space in which patients could voluntarily offer symptom and treatment information to a broader community of similarly diagnosed individuals, PatientsLikeMe altered policy conversations about what was feasible and palatable to the American public by demonstrating that many people agreed with its openness philosophy (as opposed to traditional privacy policies) of sharing medical and personal information for the good of research and social support.

Other paradigm-breaking websites include the Google-owned 23andMe (www.23andme.com), which uses genome sequencing technology to deliver personalized risk profiles for potentially inherited health conditions; Nike's participative site for runners seeking to compare their physical responses (www.NikePlus.com); and the US Centers for Disease Control and Prevention (CDC) site's use of social media microblog feeds such as Twitter to monitor potential disease outbreaks (www.cdc.gov).

What these and other such sites have in common, according to *Wired* magazine's executive vice president, Thomas Geotz, is two crucial components: personal engagement and a willingness to share and rely on data.⁵ Indeed, public engagement in health issues is evident in data from the National Cancer Institute's Health Information National Trends Survey (HINTS), which indicates a steady rise in Internet use for surveyed Americans 18 years and older from about 45 percent in 2003 to 75 percent in 2008. Across administrations of the HINTS, roughly half of the online population reported having looked for health information —either for themselves or a loved one—in the previous 12 months. An estimated 90 million Americans went online in 2007 to look for health information in one form or another.⁹

In terms of Health 2.0 technologies, HINTS began tracking respondents' use of social networking sites such as Facebook and LinkedIn in 2008. The overall usage rate for these technologies hovered around 23 percent in the first survey, but analyses uncovered a strong inverse relationship between social media use and age: the rate for 18-to 24-year-olds was about 74 percent. In fact, digital citizens in this age range were nearly 48 times more likely to use social networking sites than those in the oldest range (65+) when controlling for other sociodemographic factors.¹⁰ The use of social media in the service of personal health information is likely to rise as usage patterns increase across age groups in the future.

With respect to data usage, the story is more nuanced. US Department of Education surveys drive home the fact that average Americans lack the numeric literacy needed to interpret complex statistical presentations and understand concepts such as probability, relative risk, and association. Even well-educated decision makers can err when forced to rely on quick, heuristic processes to digest information. Too much data can lead to "data smog"¹¹ among many audiences, leaving them confused as to what to do next. At the same time, most Americans acknowledge the importance of data in making health-related decisions, and they routinely benefit from data in other parts of their lives presented in simple and intuitive interfaces like dashboards, weather maps, and iTunes-like usage bars.⁶

Taken together, the evidence suggests that we are just entering the diffusion curve for personal participation in health information. Researchers and policymakers must ensure that the platform for public participation is both easy to use and reliable. Failure to do so will lead to confusion at best, and it could result in dangerous health practices or exposure to exploitative business practices by unscrupulous commercial interests—the electronic frontier's "snake oil salesmen"—at worst.

Table 1 lists a couple of areas identified by the TMSP panel in health-related areas that would merit attention by funding agencies, scientists, and developers. The goal in presenting these topics as research opportunities is not to diminish their immediate relevance but to improve the efficacy of consumer-facing health applications through proven scientific techniques as part of the national strategy of moving evidence-based practices into real-world health environments.

CLINICAL HEALTH INFORMATION

Medicine has become one of the most information-intensive sectors of the economy—the National Library of Medicine (NLM)'s bibliographic database MEDLINE (www.nlm.nih.gov/databases/databases_medline.html) added some 712,000 new publications in 2009 alone. In addition to digesting the burgeoning evidence of published biomedical literature, medical practitioners are also looking for ways to contribute data to accelerate scientific discovery and improve medical processes. The Institute of Medicine's vision of a "learning healthcare system" emphasizes data fluidity as information moves transparently through levels of stewardship from individual practices, to hospital

administrations, to state health departments, and ultimately to federal policy and regulatory bodies.¹³

Biomedical scientists are also engaging in experiments to connect their data resources in ways that will accelerate discovery. One of the most notable accomplishments of the past century occurred in 2003, when thousands of scientists working in hundreds of laboratories around the globe completed mapping the more than three billion base pairs comprising the human genome. The Human Genome Project stands as an immutable testament to the power of TMSP in the scientific realm. The challenge now is to move beyond that milestone to identify those genetic characteristics that can improve the precision and accuracy of treatments in an age of personalized medicine. To do this, research institutions must work closely together to develop the next generation of high-throughput computing systems. These technologies should extend cutting-edge scientific discovery from the purview of any one country to a worldwide endeavor.

Today's challenge, then, is to harness the power of health IT to create a world-class infrastructure for biomedical discovery and practice. Within this environment, epidemiological data volunteered by public health officials across the globe could quickly be combined to thwart a dangerous pandemic. Articles by researchers of all nationalities will contribute to the collective intelligence of medicine, a trend presaged by the geometric increase in international access to the NLM's online bibliographic resource MedlinePlus (www.nlm.nih.gov/medlineplus). Nongovernmental organizations such as Doctors Without Borders and the International Red Cross and Red Crescent Movement have already begun to benefit from the enhanced civic participation in global medicine encouraged by the strategic use of TMSP applications.

It will be incumbent on user-interface researchers to develop the information environments that reinforce the shared goals of creating a safe, understandable, equitable, and effective clinical health system.¹⁴ Medicine 2.0, like Health 2.0, must be informed by technologies that enable participation, ensure the safe dissemination of high-quality data, and facilitate collective intelligence within communities of practice. Social networking sites for medical practitioners, like Sermo (www.sermo.com), already show the promise of this approach. With the increasing use of standards-based EHRs, new opportunities for collaborative diagnosis, expert review, and continuing professional education will emerge.

Table 2 lists some of the research questions that may guide TMSP development in the next phase of medical science and practice.

POPULATION HEALTH INFORMATION

In spring 2010, HHS and the Institute of Medicine announced a joint initiative to use the power of TMSP to enable community action based on a transparent availability of community-based data. The Community Health Data Initiative (www.cdc.gov/nchs/data_access/chdi.htm) is part of a broader, "open government" push to use the resources created by tax dollars to directly benefit taxpayers. As Figure 2 shows, it encourages the use of mashups, social networking tools, enhanced search, and other technological innovations to support active community participation based on credible public-health sources.

The Community Health Data Initiative is essentially an experiment in TMSP within the population health sphere. It aims to give community planners, policymakers, health-services professionals, public health advisors, and even general citizens access to the right tools to create healthier communities. To be successful, community architectures must incorporate the lessons learned from decades of public health science oriented around principles of

community-based participatory research with an emerging evidentiary base in eHealth—the use of electronic processes and communication to support health. They also need to utilize the best data mining, visualization, and aggregation techniques available.

As with clinical medicine, many issues confronting public health professionals have global implications. Greater population mobility has made it easier for pathogens to spread beyond local sources, increasing the risk of global pandemics. On the environmental side, continued destruction of the rain forests in the southern hemisphere will have devastating long-range effects on both global warming and the production of life-saving pharmaceuticals. If not regulated from an international perspective, dangerous industry practices can quickly contaminate the food supplies of multiple countries. Once it recognized that it was losing the public health battle in the US, the tobacco industry began marketing aggressively elsewhere, pushing worldwide the mortality rate due to tobacco consumption from 5 million lives in 2008 to an estimated 10 million by 2020 and an estimated 1 billion by the end of the century (World Health Organization).

A question to consider, then, is whether TMSP can help solve global health problems. Perhaps a positive answer can be found in the use of participative media to address the challenges of publicized health crises. For example, following the 12 January 2010 earthquake in Haiti, the Red Cross reportedly raised some \$5 million in individual \$10 donations through its "text 'Haiti' to 90999" campaign by July. It is easy to see how new participative technologies could catalyze other international relief efforts. Organizations such as Doctors Without Borders and Livestrong have begun to exploit such technologies to encourage civic responsibility for remedying hunger epidemics, unsafe drinking water, and cancer.

Table 3 highlights some of the public-health-related research questions TMSP could help address both locally and globally.

In the industrial age of medicine, healthcare was a highly technologized commodity offered to patients in a reactive, mass-produced way. In the information age, medicine must evolve to become predictive, personalized, preemptive, and participative.¹⁶ This new paradigm will enable citizens to work together with medically trained professionals to extend life while reducing healthcare costs and thereby preserving the social safety net. The recently passed HITECH Act promises to accelerate US investment in health technologies that promote personal, patient, and community empowerment.

The panelists who convened in April 2010 considered TMSP research opportunities within each of the three health information spheres identified by the NCVHS report. In the area of personal health, they considered a citizenry that is increasingly engaged in health issues and willing to contribute personal data to the larger public commons if doing so accelerates progress against disease. In the clinical sphere, the panelists explored growth in the global community of medical practice as clinicians seek to make sense of the exploding database of scientific medical findings. And in the population sphere, they looked at ways in which a national priority for transparency and data sharing could be applied to communities as local leaders seek ways to improve conditions through regulation and awareness.

In its review of TMSP opportunities, the panel was fully cognizant of what is at stake. The gains from science-based medicine are relatively recent, with life expectancy doubling during the 20th century as a result of adherence to best evidence. The challenge today is to build on that foundation of success by extending the benefits of medical science to all citizens. In this new era of medicine, it will take the work of many scientific disciplines to effect the changes needed for promoting ongoing advances without causing unanticipated harm. Computer science can contribute by creating the architectures needed to promote

social participation. In moving forward, however, high-quality, rigorous research is needed to ensure that Health 2.0's benefits match and hopefully exceed those gained in the past century.

Biographies

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Figure 1.

Research opportunities in developing the national health information infrastructure. Technology-mediated social participation systems have applications within the spheres of personal, clinical, and population health information.



Figure 2.

The Community Health Data Initiative encourages the use of mashups, social networking tools, enhanced search, and other technological innovations to support active community participation based on credible public-health sources. Source: Department of Health and Human Services (HHS).

Table 1

Research opportunities within the personal health information sphere.

Opportunity	Research questions
Promoting healthy living. Public health evidence suggests that the risk of death from the biggest killers in the US— heart disease, malignant neoplasms, and cerebrovascular disease—can can be cut 50 to 75 percent by lifestyle adjustments alone.	How can social media applications be used to reach citizens with the right information (for example, personalized and persuasive content) at the right time to inform health behaviors and decisions? What can smartphones and other personal sensing devices offer to improve the living conditions and environment in which citizens may thrive (for example, social games that encourage exercise, augmented reality tools to collect health information at the point of purchase, and ubiquitous air quality sensors)? What evidence-based recommendations for user interface development can "nudge" behavior in healthy ways (for example, through work on consumer incentives, mental mappings, default options, behavioral feedback, accommodation for error, and decision-making structures)? How can social technologies be used to spread and maintain social norms and policies that will encourage healthy living?
Supporting patients with acute or chronic disease. Studies suggest that a patient's sense of personal motivation can be a vital contributor to the success of treatment for acute conditions along with vitality and safety when confronting chronic conditions.	How can researchers construct participative health environments to support a patient's sense of autonomy (personal control over health decisions), competency (mastery over self-management skills), and connectedness (social support from relevant others)—all factors implicated by psychological research to influence the intrinsic motivation of individuals? ¹² How can home health environments be constructed to move long-term care out of institutions and back into the home, without losing the support of both personal and professional care teams? What can patients do to assist researchers in accelerating progress toward understanding the etiology, prognosis, and treatment of disease and injury? How can researchers collect a patient's personal medical information in a way that improves data fluidity among all members of the care team, including the patient?

Table 2

Research opportunities within the clinical health information sphere.

Opportunity	Research questions
Delivering on the "meaningful use" criteria for certification of health IT. When the US Congress passed the HITECH Act in 2009, it stipulated that the implementation of new health information technologies must follow guidelines for "meaningful use" to qualify for monetary incentives. Not coincidentally, many of the emerging guidelines focus on repairing the rifts that exist within the fragmented US system of care. TMSP principles may help health system designers deliver on the promise of meaningful use in the next generation of health IT development.	How can participative technologies be used to align forces for quality improvement across components of an interconnected health production system? How can hospitals, health maintenance organizations, medical practices, and other communities of care work together to identify and implement the best evidence-based practices available for optimizing patient outcomes? How can virtual associations of patients and medical practitioners be used to create a connective healthcare system that is both relationship-oriented and that can extend beyond traditional geographic boundaries of rural versus urban or well-resourced versus underserved? What protections and policy changes must be put into place to safeguard the privacy of personal health information, while encouraging data liquidity for quality improvement and research throughout the system?
Accelerate discovery and translation within biomedical science. In August 2009, National Institutes of Health director Francis Collins identified the need to develop high throughput computing systems to enable a new era of data- intensive discovery in health science.	How can the next generation of scientific "collaboratories" be expanded to include input from both the clinical and public health domains, and from other traditionally disconnected paths for discovery? What collaborative structures must be developed to solve the knowledge-management problem in science funding—that is, to enable scientific communities to discover what it is that they collectively know so as not to waste precious scientific resources? What analytic structures are needed to improve communications between scientists in a milieu of exploding data resources and burgeoning repositories of scientific publication? How can a paradigm of data sharing be fostered in a culture that has traditionally valued data hoarding and individual competition? What can be done to extend the global reach of health information, so that the evidence gained in one country can be brought to bear on problems confronted by other countries?

Table 3

Research opportunities within the public health information sphere.

Opportunity	Research questions
<i>Communities of health.</i> Under a push for "open government" as enabled by Web 2.0 technologies, HHS launched an initiative to explore the use of federally collected health information to improve the conditions of communities throughout the nation.	How can extant theories of community-based participatory research be used to create applications that empower community improvement? How should best practices in metadata documentation evolve to enable longitudinal and cross-sectional mashups of multiple data sets? What user interface requirements for presenting data to lay audiences would enhance understanding and avoid erroneous conclusion making? How can user-generated data be incorporated into the national health information network in a way that supports community health and does not fall prey to the co-optive influence of special interests such as the tobacco lobby?
Infodemiology. ¹⁵ Once public health discourse becomes digitized on the Web, epidemiologists should be able to mine online data for rapid assessments of potential public health threats. The Google Foundation, for example, uses online search behavior related to influenza to identify potential disease outbreaks in near-real time.	What computational techniques can be used to monitor public health threats in digital environments while respecting First Amendment rights protecting all speech? How should the assumptions of traditional epidemiology be modified to meet the expanding opportunities for surveillance in an online environment in terms of coverage, validity, and reliability of indicators? In what ways can "citizen epidemiologists" enhance data structures in the surveillance grid by volunteering information? How could disease registries, hospital administrative data, and new participative surveillance resources be combined to improve diagnostic decision making?
Collective altruism.	What business models will allow developed countries to assist in global relief efforts in sustainable ways? How do the conditions that promote altruism from a social psychological perspective manifest within a massively connected, distributed community environment? What can be done to transcend geopolitical and cultural barriers as communities identify the superordinate goals driving cooperation?