

Participating in Health

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INTRODUCTION

In 2006, leaders within the National Health Service in the United Kingdom made a prescient observation: in order to extend the lives of its citizens while at the same time preventing an economic meltdown of its healthcare budgets, the country must foster a patient-led revolution in the ways in which health is constructed. “Patient and public involvement are at the centre of the modernization of the NHS in England,” the leaders 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 ocean, industry leaders in computing observed that the fundamental changes inherent in the Web 2.0 movement – changes that emphasized participation, shared data, and collective intelligence² – might enable a similar revolution in health and healthcare within the U.S. “Health 2.0,” as some have called it,³ would allow U.S. citizens to take a more proactive stance in relation to their own health and healthcare; even to the point of assisting in the acceleration of discovery in biomedical science, of lobbying for healthier laws and healthier environments, and in engaging more directly in medical decision making.

Tensions exist, however, in discussions of how Health 2.0 technologies might be deployed in ways that accelerate benefits without jeopardizing gains made in the past century over protecting the health and safety of the population.⁴ Public health officials have repeatedly expressed concerns that some information (such as the personalized risk profiles offered by genomic sequencing companies) may be overwhelming or even misleading to individuals struggling to make life and death decisions in the context of nascent or unsettled science.⁵ Meanwhile, medical professionals worry about the poor quality of user-generated content on the unregulated web, epitomized by groups that advocate against receiving immunizations as a type of “government conspiracy.”

The good news is that evidence is beginning to accumulate from the psychological and organizational sciences to inform the debate.⁶ The opportunity is at-hand for computer scientists to work in tandem with biomedical researchers, policy specialists, and medical practitioners to create the blueprint for how Technology Mediated Social Participation (TMSP) can be used to usher in a new era in medicine.

A STRATEGIC INVESTMENT IN HEALTH INFORMATION TECHNOLOGY

Just what are the opportunities for investing in participative technologies within health and healthcare? Where do these opportunities lie within the larger framework of a strategic plan for health, at least in the U.S.? To answer that question it is worthwhile to consider a document produced by the National Committee on Vital and Health Statistics released in the autumn of 2001. The name of the report was *“Information for Health: A Strategy for Building the National Health Information Infrastructure.”* Released in the wake of the 9-11 terrorist attacks in the U.S., the report called for an end to fragmentation within data systems. It was time to create “an effective, comprehensive health information infrastructure that links all health decision-makers, including the public,” a preface to the report declared.

In general, there were three spheres of participation that were outlined by the report in considering the role of health information in the national agenda. There was a personal sphere, made up of individual citizens looking to make the best use of health information to inform the vital decisions associated with their own health and the health of their loved ones; there was a clinical sphere, made up of practitioners and biomedical scientists communicating with each other on the particulars of individual cases and the best evidence needed for treatment; and there was a population sphere, made up of public health officials and communities seeking to put in place the best policies to protect all members of the population equitably. Each of the spheres was essential for producing health in the 21st Century, authors of the report argued. A computer-based infrastructure was needed to ease

the flow of information from one sphere to the next seamlessly, while allowing connections by relevant stakeholders through distributed network technologies. Interconnecting the already existing biomedical informatics structures between hospitals would be especially challenging. Committee members called for the creation of a national office dedicated to the task of coordinating information technology development within and between hospitals.

Release of the 2001 *National Health Information Infrastructure* report was just one step in an ongoing effort to modernize the U.S. health system through health information technology. In 2004, the President of the United States included a goal in his State of the Union address to connect the majority of Americans to “Electronic Health Records” (EHRs) by 2014. Following recommendations from the National Health Information Infrastructure report, a special office (referred to generally as the “Office of the National Coordinator”) was formed within the Department of Health and Human Services to oversee efforts in establishing a foundation of information technology for health and healthcare.

In 2009, once it had become obvious that movement toward the national goal of diffusing EHRs was lagging, Congress passed the “*Health Information Technology for Economic and Clinical Health*” (HITECH) act as part of the American Recovery and Reinvestment Act. The HITECH portion of the stimulus bill offered funds to stimulate adoption of EHRs through monetary incentives for the “meaningful use” of Health Information Technology in the short run, and to penalize lack of meaningful use (at least for Medicare patients) in the long run. The definition of “meaningful use” has been under some debate, but discussions have been influenced by a 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 of a national health information infrastructure have often been limited to conversations around Electronic Health Records (EHRs), the national perspective still

revolves around each of the three spheres identified in the 2001 blueprint. The Department of Health and Human Services remains committed to the notion that patients should be empowered with tools to pursue the best health strategies for themselves and their families as identified within the personal sphere, while interacting with a responsive system of care distributed across areas of primary care and specialization as indicated by the clinical sphere. It also understands that participative efforts between individuals and health systems will only pay off at the population level if communities also show involvement by altering policy and improving incentives.

In that context, we will consider the research questions that should drive development and utilization of TMSP systems across each of the three spheres identified by the Committee on Vital and Health Statistics (see Figure 1, for an overview). The research questions included within each section were generated by a panel of invited experts convened through support of the National Science Foundation on April 23-24, 2010.

<Place Figure 1 about Here>

PERSONAL HEALTH INFORMATION

In 2001, when the National Health Information Infrastructure report was first being released, predictions were mixed as to whether patients would have the capacity to participate fully in the online flow of medical information as it was proposed in the report. In fact, around the same time the report was being published, 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 goals through restrictive interpretations of the privacy clauses.⁸ Patients were often dissuaded from engaging too much in online discussions of health, with epithets

such as “cyberchondria” being bantered about as a suggestion that too much patient engagement might be a bad thing.

In spite of the warnings, the U.S. population was not inhibited in their use of the Internet for information on health conditions, drugs, exercise and diet, doctors and hospitals, insurance providers, and a host of other health 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 (e.g., see <http://e-patients.net/>).

Patients also found strength in numbers. Early support communities such as the email lists at Association of Cancer Online Resources (ACOR) removed the sense of isolation felt by individuals struggling with the realities of a diagnosed ailment. Those early online communities have since been augmented by more sophisticated social networking sites such as the participative data-sharing site, “*PatientsLikeMe*.” The *PatientsLikeMe* site was 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 over what was feasible and palatable to the American public by demonstrating that many people agreed with their “openness philosophy” (as opposed to “privacy policy”) of sharing medical and personal information for the good of research and social support. Other paradigm-breaking Websites included the Google-owned company “23andme,” which uses genome sequencing technology to deliver a personalized risk profile of potentially inherited health conditions; Nike’s online participative site for runners seeking to compare their physical responses to others; and the CDC’s use of social media microblog feeds such as Twitter[®] to monitor, and inform others, of potential disease outbreaks.

What these sites all have in common, according to Executive Vice President of Wired magazine Thomas Geotz, is two crucial components: (1) personal engagement and (2) a willingness to share and rely on data.⁵ Indeed, evidence of public engagement in health issues can be found in the data collected through the National Cancer Institute's Health Information National Trends Survey (HINTS). Data from HINTS have shown a steady rise in Internet use for Americans aged 18 years and older, from a penetration rate of about 45% in 2003 to 75% in 2008. Across administrations of the HINTS, roughly half of the online population reported having looked for health information – either for themselves or for a loved one – in the previous 12 months. In 2008, an estimated 90 million Americans had reportedly gone online in the previous year to look for health information in one form or another.⁹

In terms of engagement through Health 2.0 technologies, HINTS began tracking respondents' use of social networking sites, such as Facebook® and Linked-in®, in 2008. Penetration rates for these technologies hovered around 23% overall in the 2008 survey; however, analyses uncovered a strong inverse relationship between social media use and age, with a penetration rate up to 74% for the online segment aged 18-24 years. According to these analyses, digital citizens in the youngest age range within the survey were estimated to be 47.85 times (95% CI =27.92 -82.00) *more likely* to engage in social media sites than those in the oldest range (65+) when controlling for other sociodemographic factors.¹⁰ The use of social media in the service of health communication is likely to rise as usage patterns increase across age groups in the future.

With respect to data usage, the story is more nuanced. Surveys by the U.S. Department of Education drive home the point that most Americans simply do not have the numeric literacy needed to interpret complex statistical presentations. Concepts such as probability, relative risk, and statistical association can be elusive to the lay public. Even well-educated decision

makers can be prone to making routine errors of judgment when forced to rely on quick, heuristic processes for digesting information. In fact, too much data can lead to a type of “data smog”¹¹ among many audiences, leaving them confused as to what to do next. At the same time, a majority of Americans acknowledge the importance of data in helping them make decision about their health and the health of their loved ones. These same Americans benefit from data routinely in other parts of their lives through carefully constructed interfaces (dashboards, weather maps, iTunes-like usage bars, etc.) to make use of quantitative information presented in ways that are intuitive and easy.⁶

Taken together, the evidence suggests that we are at the beginning of the diffusion curve for personal participation in health information. Work must be done to ensure that the platform for public participation is constructed in a way that is usable and reliable to the general population. Failure to do so could lead to confusion in the most benign case, or it might lead to dangerous health practices or exposure to exploitative business practices by unscrupulous commercial interests (i.e., “snake oil salesmen” on the electronic frontier) in the worst case.

In Table 1 we present just some of the topics identified by a TMSP working group in health-related areas that would merit attention by funding agencies, scientists, and developers. The goal in presenting these topics as targets for research and development is not to diminish their immediate relevance; rather, the goal is to elevate the importance of improving the efficacy of consumer-facing health applications through proven scientific techniques as part of the national strategy toward moving evidence-based practices into real world health environments.

Table 1. Targets for research within the personal health information domain.	
<i>The Opportunity</i>	<i>Research Questions</i>
Promoting healthy	Public health evidence suggests that the risk of death from the biggest killers in the U.S. according to the Centers for Disease

<p>living</p>	<p>Control and Prevention (heart disease, malignant neoplasms, and cerebrovascular disease) can be cut by 50-75% by adjustments to lifestyle alone. Following are some opportunities for investigation given recent changes in the media landscape.</p> <ol style="list-style-type: none"> 1. How can social media applications be used to reach citizens with the right information (e.g., personalized and persuasive content) at the right time to inform health behaviors and decisions? 2. What can smartphones and other personal sensing devices offer to improve the living conditions and environment in which citizens may thrive (e.g., social games that encourage exercise; augmented reality tools to collect health information at the point of purchase; ubiquitous air quality sensors)? 3. What evidence-based recommendations for user interface development can be used to “nudge” behavior in healthy ways (e.g., through work on consumer incentives, mental mappings, default options, behavioral feedback, accommodation for error, and structures for decision making)? 4. How can social technologies be used to spread and maintain social norms and policies that will encourage healthy living?
<p>Supporting patients with acute or chronic disease</p>	<p>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. Relevant research questions include the following:</p> <ol style="list-style-type: none"> 1. How can participative health environments be constructed to support a patient’s sense of autonomy (i.e., 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 2. 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? 3. What can patients do to assist researchers in accelerating progress toward understanding the etiology, prognosis, and treatment of disease and injury? 4. How can a patient’s personal medical information be collected in a way that improves data fluidity among all members of the care team, including the patient?

CLINICAL HEALTH INFORMATION

Medicine has become one of the most information-intensive sectors of the new economy, with some 712,000 new publications added to the National Library of Medicine's bibliographic database MEDLINE® in 2009 alone. In addition to digesting the burgeoning evidence base of published literature in biomedicine, medical practitioners are also looking for ways of contributing data back to the community as a way of accelerating scientific discovery and improving medical processes. Visions for a "Learning Healthcare System," as articulated by the Institute of Medicine, emphasize the fluidity of data as information moves transparently through levels of stewardship from individual practice, to hospital administration, to state departments of health, and then ultimately to federal policy and regulatory bodies.¹³

Biomedical scientists are also engaged in ongoing experiments to connect their data resources in ways that will accelerate discovery. Perhaps one of the more notable scientific accomplishments of the last century came when literally thousands of scientists working in hundreds of laboratories around the globe completed mapping of the 3 billion + base pairs comprising the human genome. That single accomplishment stands as an immutable testament to the power of TMSP in the scientific realm. The challenge now will be to move beyond that singular milestone to identify the genetic characteristics that can improve the precision and accuracy of treatments in an age of personalized medicine. To do this, as emphasized by the director of the National Institutes of Health in August 2009, the nation's research institutions must work closely together to identify the next generation of high throughput computing systems to accelerate collaborative discovery based on a foundation of petabyte computing and intensive collaboration. Moreover, the global reach of these

technologies should extend the collective neighborhood of science from the purview of any one country to the expanded capacity of a world-wide endeavor.

The challenge in medicine today, then, is to harness the power of information technology to create a world-class infrastructure for biomedical discovery and practice. Within this environment, epidemiological data volunteered by public health officials in Sichuan, China could be combined with data volunteered simultaneously by other countries around the globe to thwart a contagious pandemic before it spreads. Research and practice articles contributed from around the world can contribute to the collective intelligence of medicine as the global community of practice expands beyond borders, a trend presaged by the geometric increase in international access to the National Library of Medicine's online bibliographic resource: Medline Plus. Nongovernmental organizations such as "Doctors without Borders" (Médecins Sans Frontières) and the International Red Cross / Red Crescent have already begun to benefit from the enhanced civic participation in global medicine encouraged by the strategic use of TMSP applications.

As data flows increase, it will be incumbent on user interface researchers to develop the information environments that reinforce the shared goals of creating a health system that is safe, understandable, equitable, and effective.¹⁴ Medicine 2.0, like Health 2.0, must be informed by technologies that enable participation, protect the flow of high-quality data, and facilitate the evolution of collective intelligence within communities of practice. Social networking sites for medical practitioners, like SermoTM, already show the promise of this approach. As standards-based Electronic Medical Records become increasingly used, new opportunities for collaborative diagnosis, expert review, and continuing professional education emerge. In Table 2, we provide a listing of some of the research questions that may serve to guide TMSP development in the next phase of medical science and practice.

Table 2. Targets of opportunity within the clinical health information domain.	
<i>The Opportunity</i>	<i>Research Questions</i>
Delivering on the “meaningful use” criteria for certification of Health Information Technology (HIT)	<p>When Congress passed the HITECH Act in 2009, it stipulated that the implementation of new health information technologies must follow guidelines for “meaningful use” in order to qualify for monetary incentives. Not coincidentally, many of the guidelines that are currently emerging focus on repairing the rifts that currently exist within the fragmented system of care present in the U.S. Principles of TMSP may help health system designers deliver on the promise of meaningful use in the next generation of HIT development, as illustrated by the following questions.</p> <ol style="list-style-type: none"> 1. How can participative technologies be used to align forces for quality improvement across components of an interconnected health production system? 2. How can hospitals, health maintenance organizations, medical practices, and other “communities of care” work together in identifying and implementing the best evidence-based practices available for optimizing patient outcomes? 3. 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 vs. urban or well-resourced vs. under-served? 4. What protections and policy changes must be put into place to safeguard the privacy of personal health information (PHI), while encouraging data liquidity for quality improvement and research throughout the health system?
Accelerate discovery and translation within biomedical science	<p>In August 2009, NIH Director Francis Collins identified the need to develop high through-put computing systems to enable a new era of data-intensive discovery in health science. Following are some areas in which TMSP principles can inform the discovery and translation of new life-saving treatments.</p> <ol style="list-style-type: none"> 1. 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? 2. What collaborative structures must be developed in order 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? 3. What analytic structures are needed to improve communications between scientists in a milieu of exploding data resources and burgeoning repositories of scientific publication? 4. How can a paradigm of data sharing be fostered in a culture that has traditionally valued data hoarding and individual

	<p>competition?</p> <p>5. 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?</p>
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POPULATION HEALTH INFORMATION

In the spring of 2010, the Department of Health and Human Services worked jointly with the Institute of Medicine to announce an initiative aimed at using the power of TMSP to enable community action based on a transparent availability of community-based data. Termed the “Community Health Data Initiative,” the effort is part of a broader “open government” push designed to offer the resources created by tax dollars to the direct benefit of taxpayers. As illustrated in Figure 3, the initiative encourages the use of data “mash ups,” social networking tools, enhanced search, and other technological innovations to encourage active community participation based on credible sources of public health data.

<Place Figure 2 about Here>

In essence, the Community Health Data Initiative is an experiment in TMSP within the population health sphere. Its emphasis is on giving community planners, policy makers, health services professionals, public health advisors, and even general citizens access to the tools they need to create healthier communities. To succeed, the best community architectures will undoubtedly incorporate the lessons learned from decades of public health science oriented around principles of “community-based participatory research” with an emerging evidentiary base in the area of “eHealth” (i.e., the use of electronic processes and communication to support health). It will also need to utilize the best data mining, visualization, and aggregation techniques available.

As with the practice of clinical medicine, many of the issues confronting public health professionals have global implications. With increased mobility across borders, many of the

locally contained pathogens can be easily transported, creating an increased risk for global pandemics. On the environmental side, destruction of the rain forests in the southern hemispheres will have long range effects both on global warming and on the production of life-saving pharmaceuticals around the globe. Dangerous industry practices if not regulated with an international perspective can quickly contaminate the food supplies of multiple countries. The tobacco industry, once it recognized that it was losing the public health battle in the U.S., has aggressively pursued a global marketing with the effect of pushing global mortality from tobacco consumption from 5 million lives lost in 2008 to an estimated 10 million by 2020 and a total of 1 *billion* by the end of the century.

One of the questions, then, is to consider whether TMSP can serve as a solution to global health problems. Perhaps a positive answer to that question can be found in the use of participative media to address the challenges of publicized health crises. For example, by July of 2010 the Red Cross had reportedly raised some \$5 million dollars -- \$10 at a time -- through its successful text messaging campaign following the January 12 earthquake in Haiti (i.e., “text ‘Haiti’ to 90999). It is easy to see how other types of global relief efforts could be catalyzed by a strategic use of the new participative technologies. Global organizations such as “Doctors without Borders” and the “Live Strong Foundation” (formerly, the Lance Armstrong Foundation) have begun to make use of participative media to encourage civic responsibility for global epidemics of hunger, unsafe drinking water, and cancer.

Following are a few of the research questions that studies in the area of TMSP could help address both locally and globally.

Table 3. Targets of opportunity within the public health information domain.	
<i>The Opportunity</i>	<i>Research Questions</i>
Communities of Health	Under a push for “open government” as enabled by Web 2.0 technologies, the Department of Health and Human Services has launched an initiative to explore the use of federally collected health information to improve the conditions of communities

	<p>throughout the nation. Research directions that could be explored under this directive are as follows:</p> <ol style="list-style-type: none"> 1. How may extant theories of community-based participatory research be used to create applications that are the most productive in empowering community improvement? 2. How should best practices in meta-data documentation evolve to enable longitudinal and cross-sectional “mash-ups” of multiple data sets? 3. What are the user interface requirements for presenting data to lay audiences in a way that enhances understanding and avoids erroneous conclusion-making? 4. How can user-generated data be incorporated into the national health information network in a way that is supportive of community health and that does not fall prey to the co-optive influence of special interests (e.g., tobacco lobby)?
<p>Infodemiology¹⁵</p>	<p>Once public health discourse becomes digitized on the open Web, it should be possible for epidemiologists to mine the online data for rapid assessments of potential public health threats. An example is the use of online search behavior related influenza that led the Google foundation to beat the CDC in identifying potential disease outbreaks in close to real time. Questions for research are:</p> <ol style="list-style-type: none"> 1. What computational techniques can be used to monitor for public health threats in digital environments while respecting the first amendment rights afforded all speech? 2. 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? 3. In what ways can “citizen epidemiologists” enhance the data structures by volunteering information into the surveillance grid? 4. How could disease registries, hospital administrative data, and new participative surveillance resources be combined to improve diagnostic decision making?
<p>Collective Altruism</p>	<ol style="list-style-type: none"> 1. What are the business models that will allow developed countries to assist in global relief efforts in sustainable ways? 2. How do the conditions that promote altruism from a social psychological perspective manifest within a massively connected, distributed community environment? 3. What can be done to transcend geopolitical and cultural barriers as communities identify the superordinate goals driving cooperation?

CONCLUSION

In the industrial age of medicine, healthcare was considered to be a highly technologized commodity offered to patients in a reactive, mass-produced way. In an information age of medicine, healthcare must evolve to become predictive, personalized, preemptive, and participative.¹⁶ In this article, we report the conclusions of an invited panel of experts to explore the promise of Technology Mediated Social Participation (TMSP) – referred to by some as “Health 2.0” technologies – as a new tool for improving the health of individuals and communities. Changing the paradigm for health production in the 21st Century, some have argued, is the only way that citizens can work together with medically trained professionals to extend life while reducing costs to the social safety net of healthcare coverage. The timing is propitious. Recent passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act in the U.S. will accelerate investment in technologies that promote personal, patient, and community empowerment.

The article took as a guide the blueprint for a “National Health Information Infrastructure” (also referred to as a National Health Information Network) authored by the National Committee on Vital and Health Statistics in 2001. The blueprint called for information technology development in three spheres: (a) a personal health sphere, in which individuals use online resources to manage their own health and the health of their loved ones; (b) a clinical health sphere, in which physicians share data and science with each other to improve the quality of medical service; and (c) a population health sphere, in which communities are empowered with the data services they need to improve the health of their members.

The implications of TMSP in health were explored within each sphere. Within the personal health sphere, panelists explored the implications of a citizenry that appears to be getting more *engaged* in issues related to health and is willing to contribute their own personal *data*

into the larger public health commons if doing so would help accelerate progress against disease. Within the clinical sphere, panelists explored the implications of growth in the global community of medical practice as clinicians seek to make sense of the exploding database of scientific medical findings. Within the population sphere, the paper explored 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 how high the stakes were in health and medicine. The gains from science-based medicine are relatively recent, with life expectancy doubling during the last century as a result of adherence to best evidence. The challenge for the next century will be to build on that foundation of success, as the world's communities strive to extend 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 change 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 and rigorous research is needed to ensure that the benefits of Health 2.0 match and exceed the benefits gained in the last century.

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Figure 1. Illustrative opportunities expressed in terms of the National Health Information Infrastructure).

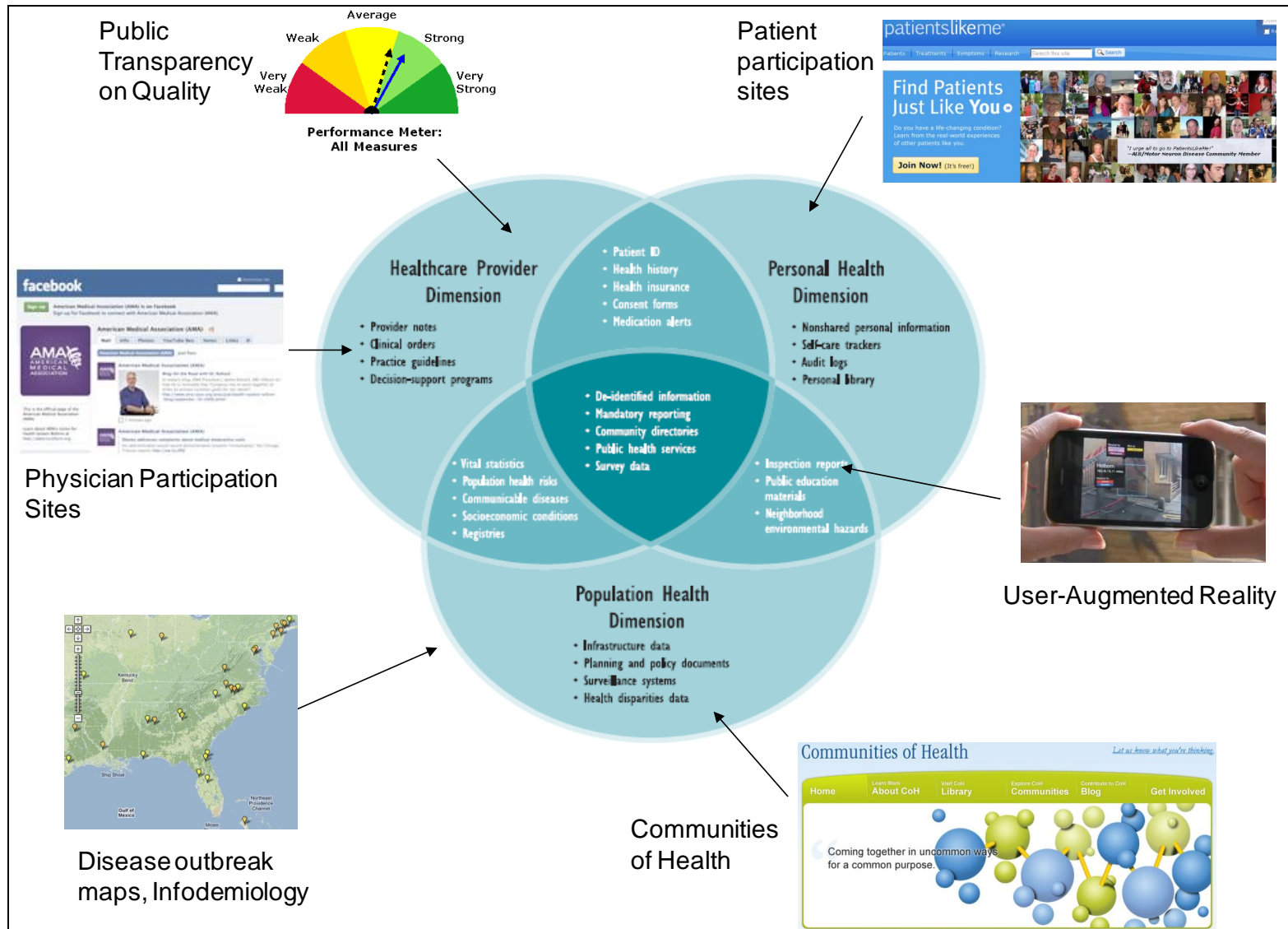


Figure 2. The DHHS Community Health Data Initiative (source Department of Health and Human Services; <http://www.hhs.gov>).

