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Realizing the Promise of Web 2.0: Engaging Community Intelligence

BRADFORD W. HESSE, MARY O'CONNELL, ERIK M. AUGUSTSON, WEN-YING SYLVIA CHOU, and ABDUL R. SHAIKH

National Cancer Institute, National Institutes of Health, Bethesda, Maryland, USA

LILA J. FINNEY RUTTEN

Clinical Monitoring Research Program, SAIC-Frederick, Inc., NCI-Frederick, Frederick, Maryland, USA

Abstract

Discussions of “Health 2.0,” first coined in 2005, were guided by three main tenets: (a) health was to become more *participatory*, as an evolution in the Web encouraged more direct consumer engagement in their own healthcare; (b) *data* was to become the new “Intel Inside” for systems supporting the “vital decisions” in health; and (c) a sense of “*collective intelligence*” from the network would supplement traditional sources of knowledge in health decision-making. Interests in understanding the implications of a new paradigm for patient engagement in health and healthcare were kindled by findings from surveys such as the National Cancer Institute’s Health Information National Trends Survey (HINTS), showing that patients were quick to look online for information to help them cope with disease. This paper considers how these three facets of Health 2.0—participation, data, and collective intelligence—can be harnessed to improve the health of the nation according to Healthy People 2020 goals. We begin with an examination of evidence from behavioral science to understand how Web 2.0 participative technologies may influence patient processes and outcomes, better or worse, in an era of changing communication technologies. The paper then focuses specifically on the clinical implications of “Health 2.0” and offers recommendations to ensure that changes in the communication environment do not detract from national (e.g., Health People 2020) health goals. Changes in the clinical environment, as catalyzed by the Health Information Technology for Economic and Clinical Health (HITECH) Act to take advantage of Health 2.0 principles in evidence-based ways, are also considered.

“People often ask, ‘If we give you your data, what are you going to do with it?’ We don’t know – that’s the point: innovators haven’t gotten their hands on it yet!”

—Dave deBronkart (e-PatientDave)(deBronkart, Kuraitis, & Kibbe, 2010)

The terms “Web 2.0,”(O’Reilly, 2005) “Health 2.0,”(Van De Belt, Engelen, Berben, & Schoonhoven, 2010) and “Medicine 2.0”(Eysenbach, 2008) have been assigned a number of different meanings since the notion of an evolving health information environment was first introduced. There has been debate over what comprises the exact tool set of this newly

Address correspondence to Bradford W. Hesse, National Cancer Institute, 6130 Executive Blvd., MSC 7365, Bethesda, MD 20892-7365, USA. hesseb@mail.nih.gov.

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expanded and evolved version of the World Wide Web, with some authors claiming that the Internet is already moving down a path toward “Web 3.0.”(Glustini, 2007; Marsh, Carroll, & Foggie, 2010) Others argue that the “Web is dead,” as design moves beyond HTML to device-based delivery systems over the general Internet (e.g., smart phones, tablets).(Fowler, 2010)

In many respects, the exact meaning of these terms is inconsequential. What is important, as argued by publisher Tim O’Reilly, in the first Web 2.0 conference in 2004, (Graham, 2005; O’Reilly, 2005) is to note that the Web is rapidly evolving from its earliest phase as an experiment in static page publishing, to an expanded set of interactive tools aimed at building upon the power of collective and individual engagement. As the technology matures and the Internet continues to insinuate itself into multiple facets of everyday life, the implications of a new Web-enabled culture will continue to play out in all sectors of society in substantive ways. Global and local commerce will change,(Friedman, 2007) as will health and healthcare,(Eysenbach, 2008) government,(Koh & Prybutok, 2003) science,(B. W. Hesse, 2008) and social discourse.(Shirky, 2008)

Implications of Health Practitioners and Researchers

Health services researchers and healthcare providers, who are increasingly aware of changes in communication technology, are asking questions about the influence these changes could have on patient care. The potential implications are vast, and myriad questions have been raised:

- How widespread is the uptake of the new participative technologies?
- Are patient outcomes threatened by “toxic” information that may make its way into the unfiltered social Web?
- Are there ways in which the care team can diffuse the damage of deleterious information? Who is benefiting from online access to user-generated data?
- Under what conditions will expanded online access lead to improved understanding for health decision-making?
- Are there aspects of the Web 2.0 phenomenon that can be marshaled by public health practitioners to improve community and individual health or advance scientific goals?
- What are the characteristics of effective design when constructing participative Web sites?
- How can the positive aspects of strategic design help improve the quality of online communities?

Organization of This Article

In this article, we evaluate what little evidence exists to address these questions and more. It is tempting to label entire aspects of the new technological environment as being wholly efficacious or wholly pernicious. However, that approach reflects naivety in thinking about the complex phenomena of 2.0 technologies. Instead, this article focuses on how the emerging ecosystems enabled by these Web 2.0-like developments may be contributing to, or detracting from, patient well-being; and it explores the role that the new information technologies can play in medicine and self-care.

Mindful of criticism that increasing online activity and exchange of information has iatrogenic effects for patients (and their healthcare providers), we explore the premise that

participative input and exposure to selected data streams can, in fact, lead to a sense of “collective intelligence” in the areas of health and healthcare. We do not explore broader contextual factors (e.g., access to care, sufficiency of resources, instrumental social support, the efficacy of biologic treatments) affecting patient outcomes and quality of care. All are important, but lie outside the scope of the article’s current focus.

After outlining three fundamental characteristics of the evolving web, we include a general definition of the concept of “collective intelligence,” as treated especially by the Web 2.0 architectural community. From there, we look to specific examples, or use cases, by which knowledge-based Web 2.0-type systems can be constructed to improve the fight against disease. We also offer caveats for areas in which poorly constructed architectures may pose risk.

Three Fundamental Characteristics of the Evolving Web

Certainly, there are hundreds if not thousands of new applications that are being connected to the Internet every year, each with its own permutation of market-driven, Web 2.0 type features. Keeping up with these experiments in new technology as they skyrocket onto the scene, and in many instances flare out just as quickly, is an impossible task. A more productive and insightful approach is to consider the major functional options the Web 2.0 technologies are offering to users across many settings. From the definition offered by Tim O’Reilly, who helped popularize the term, there were three characteristics that stand out as being especially relevant.(O’Reilly, 2005)

Architectures for Participation

The first significant change to note was the strategic decision many businesses made in moving away from Web architectures that were designed to publish static content, to creating interactive frameworks for supporting active user involvement. This was the birth of what some would refer to as the “*participatory web*.” Although the concept of the Internet as a collaboratory venue dates back to the very origins of distributed network technology,(B. W. Hesse, 2008) the emphasis of including more and more user-generated content in easy, facilitated ways is one of the hallmarks of Web 2.0 applications.

Successful examples of these newly constructed architectures from the consumer side include the video sharing service YouTube®, the social networking site FaceBook®, the embedded “comments” sections of popular eCommerce sites (e.g., Amazon.com®), and the exploding number of other participative sites in which user contribution is encouraged and promoted. Examples from biomedical science include many of the emerging cyberinfrastructure projects aimed at helping researchers to share their data in a government-supported, electronic commons.(Buetow, 2005; National Science Foundation, 2007) The National Cancer Institute’s caBIG® information network is one affirmation by the National Institutes of Health (NIH) of value in data sharing and consumer participation in the biomedical context. In addition, the NIH Public Access Policy furthers the reach of scientific resources to the public in order to improve health.(Rutten, Augustson, Doran, Moser, & Hesse, 2009)

Collective Intelligence

The second big change in Web culture is epistemological in nature. As individuals participate broadly in online venues, sharing their observations and knowledge from around the globe, venue content increasingly represents a type of “collective intelligence”: that is, an immediately accessible snapshot of what people are thinking on a particular topic at any given time. This is a view of intelligence that exceeds the abilities of any one single person. It relies on the “cognitive surplus”(Shirky, 2010) of contributing communities to tackle

important problems that exceed the grasp of any single community member. The fact that millions of users a day flock to Google and Wikipedia as their first source for information on anything from medicine to finances shows how ubiquitous users' confidence in the collective intelligence of the "net" is becoming.(B. W. Hesse, Moser, & Rutten, 2010; Lam-Po-Tang & McKay, 2010)

Understanding the ramifications of this sociotechnological shift will be necessary in order to negotiate meaningful changes in consumer protection, professional mediation, discovery, practice, and ethics in a knowledge-reliant society. Some in the science community have argued that "unleashing the power of technology mediated social participation" (of which Web 2.0 technologies are early harbingers) may be the only way to tackle some of the biggest problems confronting the population (e.g., health) in the century to come.(Ben Shneiderman, 2009)

Data as the New "Intel Inside"

The third change has to do with the value and role that advanced computational technologies can begin to place on data streams. As Tim O'Reilly has referred to data as the new "Intel Inside"(O'Reilly, 2005) for a new generation of Web-based systems. Data on consumers' use of an eCommerce Web site can be used to tailor the experience of the would-be buyer, serving up recommendations based on what other consumers with similar usage patterns have been doing. These "recommender systems"(Wei, Moreau, & Jennings, 2005) have long been a popular algorithm within such highly successful sites as Amazon.com and Netflix.com. The data can also be used to inform inventory selection and improve service to the consumer and, in turn, business investments. Polling systems can offer feedback in real time on how a particular political issue might be faring or what the status of a candidate's popular support might be.

The new data streams go beyond simple real-time calculations of user behavior. Geo-coded data within a framework such as Google Earth® can be used to steer decision-making for shoppers, travelers, or those looking for a new entertainment venue. New geography sensing applications like Foursquare, can allow users to keep track of where they have been within a city and where their friends may be heading. As these types of data become available online, new types of knowledge acquisition may become possible within the health sciences. "Infodemiology" or "Infveillance" using online usage data coupled with geo-coded spatial information might easily replace traditional surveys and field work as a more data-rich method for identifying disease trends early in time.(Eysenbach, 2009) The Web site "Data.gov" provides a timely illustration of how government sponsored data can be offered up to citizens directly as one of the services provided by a network-enabled *e-government*. (Ding, et al., 2010)

Community Intelligence and Health

In many respects, the concept of collective intelligence is nothing new. It is the premise behind the written word, the rationale behind libraries, the reason for publishing in scientific journals, and the functional justification for performing work in teams or organizations. What is new is the way in which the communication revolution is altering the channels through which information flows. These new channels enable wholly new solutions for tapping into the collective intelligence of broader groups of people in shorter amounts of time. They go beyond the "one-to-many" strategies of the broadcast age, to enable the "many-to-many" and the "many-to-one" strategies of the Web 2.0 age.(MIT Center for Collective Intelligence, 2010)

Used appropriately, these new strategies could improve collective intelligence by tapping into the parallel processes of hundreds or thousands of minds working on the same problem simultaneously.(Shirky, 2008, 2010) Used inappropriately, these same channels may lead to dysfunction, as the dark side of group process—groupthink, biased cognition, and confusion—overwhelms group members' abilities to separate the wheat from the chaff.(Keen, 2007) In addition, audiences that are bypassed by the new channels may begin to fall out of the informational loop, expanding the negative consequences of “knowledge gaps” among vulnerable populations.(Viswanath, et al., 2006) Enhanced understanding of both the positive and negative sides of the media equation, as well as a broader view of the information ecosystem, will be needed to improve the quality of patient outcomes in a period of rapidly expanding communication options.(Epstein & Street, 2007)

Building from the concept of individual intelligence, defined as the ability to apply knowledge to the task of adapting to one's environment, “collective intelligence,” can be defined as the ability of a group or community to apply knowledge in a way that allows the group to adapt and thrive in its own environment.(MIT Center for Collective Intelligence, 2010) In this paper, we chose the concept of “community intelligence” to get at the ways in which Web 2.0 technologies are supporting a better use of knowledge and data to improve health outcomes across a wide range of groups that share one or more characteristics that define them as “communities.” In this sense, we can use the term to evaluate the benefits and tensions of Web 2.0 type technologies within communities of care, communities of health, communities of science, and communities of practice.

Communities of Care

These three fundamental shifts – participation, collective intelligence, and a reliance on data –underlie some of the most important ways that health and healthcare are beginning to change as a function of paradigm shifts related to the information revolution.(Viswanath, 2005) Some of these changes may be occurring outside of the healthcare system, as when patients interact with one another in disease-related Web communities in order to interpret their own symptoms or share notes on treatment progress. Other changes may be driven by the healthcare sector, as when the U.S. government passed the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 to encourage adoption of interoperable, and data reliant, Electronic Health Records.

The Emerging Phenomenon—One of the first areas where communities began to realize the power of collective intelligence in health was through online discussion groups in the early days of dial-up computer networks. In his book *“The Virtual Community: Homesteading on the Electronic Frontier,”* writer Howard Rheingold described an online environment in which members of the electronic bulletin board group the WELL (“Whole Earth ‘Lectronic Link”) found solace in the connections they were able to cultivate with others when confronted with a disease.(Rheingold, 2000) Sometimes it was a matter of receiving a dose of emotional support, as well-wishers gathered around the afflicted community member online, offering expressions of support and hope. Other times the interactions were more informational, as when someone would ask the virtual community if anyone knew about the side effects associated with a particular treatment.

Reaching out to a virtual community with a blanket interrogative is a classic example of how community members can exploit the combined intelligence of online participants. Early studies in research and educational settings revealed that online community members who posed a simple *“Does anyone know ...”* question to the group at large stood a greater chance of obtaining a correct answer than merely questioning traditional social networks of friends or acquaintances. The probability of finding a correct answer increased proportionally to the

number of people reached by the virtual query.(Sproull & Kiesler, 1991) The concept has since been applied with some success to the online “technical support” pages of major computer and software manufacturers.(Yardi & Poole, 2009) By including access to user forums in their technical support sites, the hosting companies improve the probability that a customer will find the answer to their technical questions.

Consumers often turn to online search engines with much of the same motivation. By going to Google first to find information, they increase the probability that they will find an answer to a particular question. The probability is increased further when the search engine’s automated crawlers canvass content from discussion groups, forums, and blogs in addition to static Web content.(K. F. White, Lutters, & Komlodi, 2008)

The paradox in consumer health is that much of the information needed for patient-centered decision-making has not been available in supportive, consumable ways on the open Web. In 2001, a study by researchers at Rand found that most of the content of health-related pages at government and academic Web sites was written in language better suited for professional audiences than for consumer audiences.(Berland, et al., 2001) In 2003, the National Cancer Institute launched the inaugural administration of its biennial Health Information National Trends Survey (HINTS).(Nelson, et al., 2004) The survey indicated that although most patients preferred talking to their physicians first when confronting a health problem (49.5%; 95% CI = 48.1%-50.8%), the most frequently cited source for those having looked for health information in the previous 12 months was the Internet (48.9%, 95% CI=46.1%-51.0%).(B. W. Hesse, et al., 2005)

These trends have continued over three administrations of the survey. Trust in physicians as the preferred social source of medical information has remained high, and is, by all indications, rising. However, the predilection to go to the Web first as an easy source of first-resort has remained constant.(B. W. Hesse, et al., 2010) Interestingly, the HINTS survey has also picked up a slight increase in the number of patients reporting using email to contact their physicians, a social use of the Internet; up from an estimated 7% of the U.S. population reporting use of email in 2003 to 9.6% in 2005, and 14.6% in 2007-8 (odds ratio, 2.51; P<0.05).(B. W. Hesse, et al., 2010) This increasing trend in health-related Internet use is observed among individuals afflicted by a cancer diagnosis.(Chou, Lui, Post, & Hesse, 2010) In fact, in another analysis of the HINTS survey, we found that cancer survivors who have access to the Internet are more likely to search for health-related information than people without cancer.

This tension of patients wanting to use the information-rich environment of the Internet to inform the “vital decisions”(Fox & Rainie, 2002) of health on the one hand, and the tendency of healthcare systems to keep tight control over the vocabulary, data, and information services needed for medical care on the other, reached a boiling point during the first decade of the new century. At the beginning of the decade, professional medical organizations warned patients that “going online” before coming to a doctor’s appointment would only befuddle them. In fact, some argued, getting too involved in online health information might be a symptom of mental dysfunction, a type of “cyberchondria,”(R. W. White & Horvitz, 2009; Wickham, 2009) that should be avoided or cured. In spite of these warnings, data from HINTS and the Pew Foundation’s Internet and American Life surveys continued to document a substantial online presence of patients looking for information to supplement what they might hear from their doctors. Patients were becoming engaged in their own health conditions and in the health of their loved ones.

Profusion—By the middle of the decade, large information technology companies began capitalizing on consumers’ desires to monitor their own personal health information online

in the same way they might monitor their finances. Several companies introduced Personal Health Record (PHR) products to give consumers greater access to data about their own conditions as well as related educational materials. Google introduced “Google Health,” Microsoft introduced “Health Vault,” and Intuit introduced a companion product line to its popular Quicken® series dedicated to keeping track of medical expenses. Several health systems began experimenting with patient access to laboratory data and health monitoring tools through PHRs “tethered” to the system’s underlying Electronic Health Record.

Upping the ante on access to personal health information, two brothers launched a community-based data sharing site in 2005 called “Patients Like Me.” The site was one of the first experiments in using Web 2.0 technology to bypass the medical establishment altogether, while allowing patients to volunteer personal health information for the benefit of the greater community. In 2009, organizers of the site announced their first significant partnership with a pharmaceutical company allowing the drug development teams to mine the publically available data on patients for indications of adverse side effects and to explore areas of unanticipated efficacy. By the end of the decade, the American Medical Association acknowledged the role of the Internet in patient self-management and endorsed the “tethered” or “integrated” PHR as a means for supporting patients’ information needs.

Throughout all of these twists and turns, the role of the Internet in supporting community intelligence in health evolved in a way that was not necessarily apparent from the beginning. Many technologists theorized that the role of the Web would be to *remove* the need to interact with clinical staff for medical information, a phenomenon referred to by communication scientists as *disintermediation*. Another example of disintermediation was what happened in the travel industry when traditional travel agents, for the most part, became obsolete once consumer portals for travel planning and reservations came online. Disintermediation was also evident in banks when customers were given tools to manage their finances online and through Automatic Teller Machines.

Notwithstanding the changes seen in other industries, disintermediation has not been apparent in health; patients typically do not forego direct physician interaction in light of new technologies. In fact, they may have been relying on physicians and care teams as they made their way through the cacophony of medical terminologies, scientific studies, popular folk remedies, and vested self-interests that are present on the open Web. What may be occurring is a type of “*apomediation*,” a situation in which information appears to *surround* both the patients and their caregivers in an environment of shared decision making. (Eysenbach, 2008) Health 2.0 technologies can further facilitate shared awareness by emphasizing continuity in care through social networks, transparency of information, personal engagement, and direct access to personal health data. (Lo & Parham, 2010)

One example of designing for *apomediation* can be found in a clinical trial currently underway in Boston, MA to explore a PHR system that would make physicians’ notes available electronically directly to patients as well as to other physicians and other members of the patient’s care team. The rationale is that, as part of the medical record, a doctor’s notes can add important contextual information after a clinical visit that would be important for all members of the care team to know. Specialists, technicians, and nursing staff could all improve their situational awareness with a common framework. More importantly, the patient at the center of the care team would be cued into the nuances of his or her condition.

Patients often complain that it is difficult to remember all of the doctor’s comments in a 15 minute office consultation. Those memories can be even further compromised when bad news is given, and the patient finds himself or herself struggling to regain composure or to sorting through emotional reactions to such news. (Rothberg, et al., 2010) Open access to

physicians' notes could help jog the patient's own memories. Moreover, patients can even be offered the ability to correct or append the record if they notice an error. The premise is that "many eyes" on the record should ultimately help improve the quality of health information contained therein.(Delbanco, et al., 2010)

Boundary Conditions and Needed Research—The idea of sharing complex medical data directly with patients flies in the face of decades of practice in clinical medicine.(Goetz, 2010) Indeed, there are reasons to be concerned. Dumping too much information in a way that cannot be interpreted by patients can lead to confusion, decisional paralysis, anxiety, ill feelings, missed opportunities, and in some cases, fatal adherence errors.(Shenk, 1997) Plus, privacy concerns abound. Failing to de-identify personal health data appropriately when sharing information within communities of care can open individuals up to law suit, regulatory violations, or personal harm.

Nevertheless, there is a sound business argument to be made for sharing data in the interest of raising the situational awareness and collective intelligence of the broader care team. Not the least of these is the fact that patients are clamoring for this type of information already, as evidenced by the number of patients who go online to look for medical information in the first place.(B. W. Hesse, et al., 2010; B. W. Hesse, et al., 2005) There is also an ethical argument to be made that biodescriptive data about patients, should belong to patients. As advocates are fond of saying, "there should be no data about me, without me."(deBronkart, et al., 2010) More to the point, providing the right information to the right members of the care team at the right time is the essence of good medicine. It conforms to prescriptions from the Institute of Medicine for creating a system that is patient-centered, effective, safe, timely, efficient, and equitable. (Institute of Medicine (U.S.). Committee on Quality of Health Care in America., 2001)

A solution lies in conducting the health systems research needed to hone the protocol used to enhance the collective intelligence of the care team in ways that support desirable patient outcomes.(Lo & Parham, 2010) The multi-site "Open Notes" study is a good example of how to explore these alternatives to the status quo in safe, controlled conditions.(Delbanco, et al., 2010) Another priority will be to bring human factors research into the mix in a way that will allow system designers to construct computer interfaces, organizational protocols, and system inputs and outputs that are eminently safe and supportive.(B. W. Hesse & Shneiderman, 2007) As emphasized by the National Research Council in 2009, funding agencies should invest more in providing "cognitive support for physicians, patients, and their families."(Stead & Lin, 2009)

Communities of Health

The Emerging Phenomenon—Although the open-access experiment in clinical medicine may improve treatment and follow-up for those diagnosed with a disease or injury, another application of community intelligence would empower communities via data they need to live stronger, healthier lives in the first place. One of the simplest ways that this is already beginning to happen is in the collective reader comments of restaurants, hotels, and other venues. For example, consider the following comment from a reader of The Washington Post,("The Washington Post,") which features a weekly list of restaurants closed for health code violation:

"Closed Oct. 29 for failure to minimize the presence of vermin. Reopened Oct. 31." Note the restaurant had to "minimize" -- not eliminate -- vermin. Is [name redacted] allowed a few mice, you know, to better lure the cats? Maybe the pest threshold is greater than zero because any Chinese restaurant without vermin would lose its street cred [sic]. Also note that it took [name redacted] two days to minimize its

vermin problem; clearly the problem was too big to just stir fry away.” (“DC Restaurants with Health Code Violations (November 19, 2007),”)

With many people using the internet to help make decisions—where to eat, which doctor to visit—the reach of such comments has great implications for public establishments. The open marketplace of ideas may serve as a powerful incentive to garner positive annotations from online sources.

Similarly, health conscious consumers are beginning to band together to post tips on healthy places to run, work, and eat online. The online community began reverse-engineering the calorie counts of dishes served by local and national restaurant chains long before the Affordable Care Act legislated that calorie counts be included on restaurant menus. Portable smart-phone applications are being released to merge the calorie count information for restaurant foods with GPS location services for best restaurants, with daily counts of calories consumed, and even with calories expended through walking and exercise.

Highly portable, personal applications are beginning to channel data from many sources, social and otherwise, into the hands of consumers at the precise moment health decisions are being made. More novel applications are building information about all aspects of the environment into visual display fields of GPS devices and telephones to create an augmented view of consumer’s surroundings. If successful, the devices will bring the intelligence of the community to the points of navigation and decision-making as input to everyday action choices.

Another variant at the level of communities of health is illustrated by the National Science Foundation’s *Participatory Sensing* initiative. In one vanguard project, citizens with asthma in the greater Los Angeles area are encouraged to volunteer as data collectors in a study of the environment. The volunteers use the recording devices available through most commercially produced mobile telephones to collect data on air quality, noise levels, personal physiological responses, and GPS-determined locations as they traverse the city. They then upload the data into a program that aggregates the findings into a quantified view of local surroundings. Because the data are important to the community, motivation is high to build a knowledge base that will help the community improve the quality of its environment for the benefit of all members. The program represents a type of “citizen science,” combining the best aspects of community-based participatory research, information technology, and communication capabilities. (Burke, et al., 2006; Hand)

Profusion—Taking advantages to the community one step further, the U.S. Department of Health and Human Services initiated a program in 2010 called the Community Health Data Initiative (CHDI). The initiative is part of a broader plan to place the power of health data collected by the government directly into the hands of community organizers, so that each citizen can gain traction in making his or her community a healthier place to live. A “developers’ challenge” was issued by the department and announced jointly with the Institute of Medicine to incentivize the creation of applications that would turn government-collected data stores into informational assets. Examples include “widgets,” or code-bearing graphic elements, to channel data on infectious outbreaks to the computer desktops of community planners; dashboards, or data-based decision support tools, on Medicare fee-for-service expenditures and spending levels by state; and interactive profiles of data combined across years to give planners the capacity to track the broad-scale impact of policy changes.

Boundary Conditions and Needed Research—Each of these areas of development is based the premise that when relevant and valid data are channeled to virtual communities in ways that are reasonable and clear, virtual community members can begin to use those data

to orchestrate change. The change may be at the personal level, as when individuals negotiate healthier lifestyles by comparing their own knowledge, attitudes, or behaviors to the knowledge, attitudes or behaviors of others; or it may be at the group level, as when communities develop the critical mass needed to exert an influence on policy discussions or planning efforts. (Marsh, et al., 2010)

The way in which community data are amassed will likely have an influence on the quality of intelligence exhibited by the group. In his provocative text on *“the wisdom of crowds,”* journalist James Surowiecki recounted a series of experiments in which large groups of individuals were asked to offer their assessment of an unknown quantity, say to guess the number of jellybeans in a jar. In experiment after experiment, the average input of the entire group turned out to be a closer approximation of the “truth” than any one individual guess. In some respects, the observation is a derivation of sampling theory: that a randomly distributed set of measurements drawn from a population will begin to approximate the population’s true mean (μ) as the number of sampled measurements increases. It has been used to create a specific class of technology mediated architecture referred to as “predictor systems.” (Surowiecki, 2004)

Despite his book’s title, Surowiecki acknowledged that from social psychological experiments we know that crowds are notoriously *unwise*. For predictor systems to work they need to operate within a narrow range of operational characteristics: (a) there must be an independence of opinion; (b) there must be a method in place to poll or record votes in an unbiased fashion; (c) individuals must show competency relative to the object of estimation; and perhaps most important, (d) the group must share a mutually agreed upon goal. In addition, group heterogeneity must be obtained. If there were no diversity in the group, then the average response of the group would necessarily look like the individual response of any one member (i.e., Crowd Error = Average Individual Error – Diversity Among Individuals). (MIT Center for Collective Intelligence, 2010)

The challenge is that for many Web 2.0 situations, these conditions are simply not met. (MIT Center for Collective Intelligence, 2010) Online community forums are often populated by like-minded individuals, with little diversity in opinion or perspective. Active participants on social media sites, such as Twitter, are often distinct in personality from those who passively observe or, in the parlance of the technology, those who “lurk” on social sites. There are legitimate concerns that in the highly polarized environs of the blogosphere only the most textually vocal or saliently divergent voices will be heard. Even when the conditions are met, as when a national statistical agency portrays its carefully selected sample of representative data through the Community Health Data Initiative, the context for presenting the data must be considered in a rational way to avoid misinterpretation or a erroneous conclusions (e.g., implying spurious correlations when thoughtlessly juxtaposing disparate sets of geo-coded data).

Just as with community health interventions, work must be done to ensure that the technological platforms for community participation in health and well-being adhere to evidence-based guidelines.

Communities of Science

The Emerging Phenomenon—In 1962, on the heels of a cold war crisis in science and engineering, computer scientist Douglas Engelbart suggested that distributed computer networks could be used to “bootstrap” a new era of collective intelligence in science. (Douglas C Engelbart, 1962; Douglas C Engelbart, 1995; Douglas C Engelbart, 1998; Douglas C Engelbart & Jeff, 1999) By linking data, knowledge, and scientists together in an easy-to-use electronic environment, Engelbart reasoned, it should be possible for distributed

computer systems to “augment human intellect” in ways that would accelerate scientific progress on a number of fronts. A connective, electronic network should create a new system of abstraction in scientific thought that, if crafted correctly, would enable a new type of collective intelligence by making the knowledge of distant others immediately accessible to individual scientists in a virtual collaboratory (i.e., shared laboratory) in cyberspace. Engelbart’s paper was only the beginning of a stream of scientific innovations that would culminate 40+ years later in the emergence of a rapidly evolving World Wide Web of shared scientific knowledge; and that would accelerate discovery in unprecedented ways across many disciplines.(B. W. Hesse, 2008)

Take for example one of the greatest case studies of collective, team science in the history of medicine: documentation of the human genome. In a report by the U.S.-based National Research Council in 1989, a team of experts argued that by continuing to invest in distributed network technology (TCP-IP, or the Internet, is an example), it would be possible “someday” to document the 3 billion + base pairs of DNA comprising the human genome. (Panel on Information Technology and the Conduct of Research, 1989) Many scoffed that such a feat of collective science could be possible, but by the end of 2003 most experts agreed that scientists from around the world had been successful in documenting the full sequence of chemical base pairs making up the human genome. Examples from other scientific disciplines include:

- using networks to coordinate signals from remote sensors to give up-to-the-minute forecasting abilities in meteorology;
- the inter-institutional groupware projects in high energy physics that gave birth eventually to the global hyperlink project known today as the World Wide Web; and
- the global seismology networks allowing geophysicists to study and improve predictions for earthquakes and tsunamis worldwide.(National Science Foundation, 2007)

What the emergence of computers would do in science would not just be to accelerate data collection, but it would alter the very fabric and culture of the research enterprise.(B. Hesse, W., Sproull, Kiesler, & Walsh, 1993; B. W. Hesse, Werner, & Altman, 1988) Social scientists noted that in early examples of computer-based networks, benefits from social exchanges began to accumulate just as rapidly as benefits from data exchanges. Early adopters of the technology became more productive than their disconnected counterparts; became better connected to colleagues within the “invisible college” of research; and reported a better sense of professional identification within their disciplines.

The benefits of connecting online have been proportionally greater for scientists at remote institutions. Oceanographers in Boulder, Colorado began gaining the same access to ships and oceanographic resources as their colleagues in San Diego or Woods Hole, and scientists from around the world could gain access to the expertise that would have historically been reserved for in-person conferences or in-hallway discussions.(B. Hesse, W., et al., 1993; Sonnenwald, Whitton, & Maglaughlin, 2003; Sproull & Kiesler, 1991) Today, it is difficult to imagine any scientist who could work and thrive “off the grid” without taking advantage of at least the rudimentary benefits of electronic networking to pursue activities in their field.

Profusion—An evolution toward Web 2.0, some have argued, will push for even greater capabilities for scientists connected through the Internet.(B. Shneiderman, 2008; Ben Shneiderman, 2009) There are suggestions that because of wide-area connectivity, science is moving away from its roots within the isolating environs of the “ivory tower” to become

more integrated within the broader commons of shared knowledge and shared resources. (Finholt, 2003; Finholt & Olson, 1997; Kiesler & Sproull, 1987) The U.S. National Institutes of Health, for example, has established a policy that would make all publicly funded research available electronically to the broader scientific community within 12 months after publication.

The drive is to increase intellectual participation among all scientists, and not to reserve knowledge only for those with well-funded libraries. (Bjork, et al., 2010) The National Cancer Institute, to use another example, has developed an interoperable grid of electronic data services (called the cancer Biomedical Informatics Grid, or caBIG®) through which a global community of researchers in oncology can gain access to data on rare tissue samples, clinical efficacy trials, and cancer registry data. This type of connective infrastructure represents a “third way” between large-scale team science and the creative activities of individual scientists. It allows individual scientists (R01 grantees), as well as team-science coalitions (P-01, P-50 type grantees), to plug and play equally into the same matrix of fully compatible knowledge resources. (Buetow, 2005)

For its part, the National Science Foundation (NSF) has begun convening workshops on the topic of “Technology Mediated Social Participation.” (Ben Shneiderman, 2009) Taken by the inarguable success of such large-scale participative experiments as Wikipedia in the public sphere, computer scientists are investigating new ways in which Web 2.0 technologies can be used to improve knowledge management and accelerate discovery in the scientific sphere. “Science 2.0™”—itself a combination of expanded participation, collective intelligence, and “big data” (Waldrop, 2008)—may be the only way to tackle such large-scale scientific problems as global warming, unraveling the mysteries of the human genome, and tracing vectors of disease in a globally mobile society. (B. Shneiderman, 2008) Expanding Science 2.0 to include the contributions of lay citizens, as illustrated by the NSF’s Participatory Sensing experiment or the Susan Love “Army of Women” (Love/Avon) clinical trial experiment, promises to increase capacity while garnering a sense of good will between scientists and the public as both strive together toward superordinate goals.

Boundary Conditions and Needed Research—In spite of progress toward participatory science, there are obstacles that may prevent the broader research community from taking full advantage of Science 2.0 opportunities if they are not resolved sufficiently.

First, as anyone who has conducted a meta-analysis knows, data are difficult to aggregate if collected with disparate and unequal measures. Aggregation is even more difficult if the underlying terminologies, assumptions, and disciplinary meanings diverge across studies. A few initial efforts have begun to tackle this problem in the life sciences. The Robert Wood Johnson Foundation, as a funder for grant-related research, has begun insisting on harmonization of measures before interrelated projects can proceed. Their stated objective is to incentivize a “prospective meta-analysis” by requiring that funded grantees use the same measures across studies. More recently, the National Cancer Institute has developed an approach to data harmonization that uses the strengths of the participatory Web to create a community resource of measures developed and vetted through a variant of an online Wiki. Termed the Grid-Enabled Measures (GEM) project, this online resource provides grantees with an entrée to the caBIG® data grid while at the same time exploiting the power of an online Web 2.0 community.

Second, the incentives of science have not traditionally favored data sharing or interdisciplinary collaboration. Journals that disfavor papers with multiple authors, tenure review committees that reject scientific papers conducted on shared data, universities with archaic cost-sharing policies, and flippant comments by old paradigm professors all

contribute to the uphill battle experienced by early adopters of an “Open Science” paradigm. When possible, funding agencies are working to change those incentives by placing requirements for data sharing and transdisciplinary collaboration into their funding announcements. New generations of scientists, acculturated to the Web 2.0 norms of data sharing and collaborative innovation, will help to push changes even further. Nevertheless, as with the diffusion of all innovations, the degree to which a new style of science proliferates will depend on potential adoptees’ perceptions of usefulness of the new approach.

Third, the tools have not yet been developed to allow scientists to take full advantage of the exploding wealth of scientific information available through electronic systems. It is not uncommon for scientists at the Google foundation to process databases comprised of *billions* of records, as they seek to exploit the *petabytes* (that is, 10^{15} bytes) extracted daily through automated Web crawlers and stored in large arrays of interconnected servers called “server farms.” In the health sciences, the amount of data that will soon be made available through broad consortium arrays (such as those made available through the Genome Wide Association studies), as well as the deluge of data that could be made available regionally or nationally through the National Health Information Network, could very easily be overwhelming. New biomedical informatics tools are needed to help scientists identify and extract relevant data elements for future research, and to assist in the analysis of large-scale datasets. Web 2.0 solutions such as “collaborative searching” may very well take their place as part of the solution set.

Communities of Practice

The Emerging Phenomenon—In response to a 2010 survey by the Manhattan Research Company on behalf of the NIH, physicians began showing a high degree of penetration for Web 2.0 type technologies. Of those surveyed, 79% indicated that they had watched video clips online with 35% of respondents suggesting that they had specifically watched video clips of a professional nature. Roughly 63% indicated that they had listened to or downloaded audio files, with 20% indicating that the audio were for professional use. About 61% indicated that they had read online blogs, with 21% of respondents indicating that they had specifically read online professional blogs. The number who had authored blogs was considerably lower, with 11% writing blogs generally and only 3% authoring professional-style blogs. This ratio of people who read blogs to those who had actually written blogs is similar to blog usage within the general public. Overall though, the percentage of physicians who reported going online for professional reasons rose from 49% between consultations and 23% during consultations in 2006, to 84% between consultations and 42% during consultations in 2010.(Manhattan Research LLC, 2010)

It should not be surprising to note that over time physicians would begin to exploit the power of the Web for identifying information relevant to their work. Medicine by its nature is an information-intensive enterprise.(Institute of Medicine (U.S.). Committee on Quality of Health Care in America., 2001) The National Library of Medicine has been adding anywhere from 2,000 to 4,000 completed references to its online bibliographic *per day* since 2005, with a total of 712,000 references added in 2009. The number of Randomly Controlled Trials reported in the database has been escalating geometrically from the first trial published in 1952 to 10,000 trials published during 1995,(Chassin, 1998) and 17,683 trials published in 2009. For physicians to stay current on best practice, they must rely on standard-of-care guidelines, syntheses, and consultations with others. What may be occurring over time is that Web 2.0 media may be supplementing-or even replacing-the in-office professional consultation of previous years.

Profusion—There are several reasons why Web 2.0 usage might be increasing for physicians, though the phenomenon has not been definitively studied. The surprising number of respondents in the Manhattan survey indicating that they accessed the Internet *during consultations* (almost ¼ of the sample) suggests that many physicians are using the Internet to supplement their own knowledge in a “just in time” fashion. Chances are that many others from the 49% using the Internet for professional reasons might also be preparing for upcoming procedures, or checking the opinions of others on procedures that may be perceived as being controversial or are in flux. The canvassing ability of social networks to support physicians in asking a “Does anybody know question” of their online community of practice may be as powerful in medicine as it has been in other fields. Moreover, much of medicine is made up of procedural knowledge, with the precision of medical techniques crucial to the success of a particular procedure. Posted video content can be very effective in relating the sequencing and nuanced details of a complex medical procedure.

In parallel to the rise of the participative Web, there has been an increased emphasis on standards and guidelines for improving the consistency and quality of medical treatments. Nevertheless, as Quality Control expert Brent James demonstrated, standard guidelines can be made more relevant to the local context by giving clinical teams the ability to adapt the guideline for localized implementation. (James, 2005a, 2005b) Online communities of practice, then, could offer suggestions for how to contextualize a set of procedures for implementation at the local level; in essence, they could assist in the translation necessary to move efficacious treatments (Translation 1, or “T1” studies) into broad scale, effective utilization (“T2” or “T3” studies). (Westfall, Mold, & Fagnan, 2007)

For physicians to use practice guidelines and Web 2.0 media effectively, they must be able to rely on credibility cues to evaluate the quality of recommendations found online. Just as within other media, physicians on the open Web must consider recommendations for treatment with the same degree of scrutiny that they do in their own offices. For example, if information comes from a company marketing a specific product or treatment approach, the physician would be well-advised to scrutinize carefully the source of the information as well as the motives for posting the information initially.

Another advantage within online communities of practice is that members may be able to rely on each other for social and emotional support. Studies suggest that confronting an adverse event can be harrowing and litigiously risky in the current culture of care dominating U.S. medicine. Protected, online communities may provide an appropriate “escape valve” for physicians struggling to improve their practices without fear of reprisal. Such an escape valve may be necessary in order to create a true “culture of safety” as recommended by the Institute of Medicine. (Institute of Medicine (U.S.). Committee on Quality of Health Care in America., 2001)

Boundary Conditions and Needed Research—One of the challenges for an online professional community is the lack of cultural cues needed to separate sound professional advice from inexperienced, amateurish conjecture. Because of the life-and-death nature of medical interventions, the practice of medicine has evolved a very rigid and strict mechanism for assuring that only the most highly qualified, and sufficiently trained, individuals can be allowed to administer treatment. Physicians must share a common base of formal education and pass the exacting requirements for licensure and board certification in order to speak with recognized authority in their areas of practice. Symbols of that authority (titles, licenses, certificates, Drug Enforcement Agency numbers) may be made readily available for inspection in a physical world, but are absent in the virtual world.

Some social media sites, such as the Physician Web site Sermo, control for this problem by requiring verification of credentials before allowing professionals to join the site. This allows physicians to interact in a relatively safe environment with others who have similar degrees and [presumably] the same professional motivations. The boundary conditions are less clear in more publically accessible sites for both professional and ethical reasons. For example, should a doctor “friend” their patients on Facebook, where personal vices and voiced insecurities are sure to alter the confidential trust of the patient-doctor relationship? Is it ethical to discuss the particulars of a case online in an open patient forum, even when attempts are made to mask the identity of the patient being described? These types of questions become much more difficult to answer when the site is completely open and accessible to broad groups of people. (Lagu, Kaufman, Asch, & Armstrong, 2008)

Research is needed to understand the advantages and pitfalls of social participation in online communities of practice. Of special note, a tension appears to exist between evidence-based medicine and personal observation commonly shared in the online forum. From a human factors perspective, online communities may well be dissolving the barriers to communication that prevent equitable diffusion of best practice throughout all systems of care. Discussion boards, rich in conversation about observed side effects and implementation tips, may be filling the translational gap observed between efficacy trial and broad scale diffusion of best practice. Chat rooms may even offer biomedical researchers with a qualitative view of problems encountered at the point of care.

Observation is needed, though, to describe the limits and boundaries of an online professional environment—especially in such a high stakes field as medicine. Once the evidence on best practice becomes clearer, it will be incumbent on the professional system to integrate those lessons to incoming students through updated curricula.

Conclusions

The evolution of Internet capacity from the early examples of static Web “publishing” to the highly participative, and data-driven, innovations of Web 2.0 is having an influence on the ways in which we interact on matters related to health. In this paper, we have evaluated the premise that Web 2.0 tools can be exploited to improve the “collective intelligence” of communities participating in various aspects of the biomedical and public health enterprise.

We began by looking at communities of care, and noted that there has been an increase in the participative inclinations of patients to work in tandem with their doctors in seizing the reins of their own health. (Fox, 2008; B. W. Hesse, et al., 2010) (Fox, 2008; B. W. Hesse, et al., 2010) From survey data we know that roughly three quarters of the adult population is now online, and within that group roughly half report using the Internet to look for health information either for themselves or others. (Fox & Jones, 2009; B. W. Hesse, et al., 2010) From the perspective of the traditional medical paradigm, this influx of questioning and engaged patients represents a radical departure from medicine as usual. These developments have prompted warnings that the addictive nature of the Web may be turning the country into a nation of “cyberchondriacs.” Other observers have noted that creating a nation of activated and engaged patients is exactly what the country needs to improve quality of life, extend life expectancy, and to reduce healthcare costs. (Cayton, 2006; deBronkart, et al., 2010; Ferguson & Group, 2007; Goetz, 2010) A representative of the National Health Service in the United Kingdom, for example, explained that “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.” (Cayton, 2006)

We then looked at communities of health, and noted how the engagement of average citizens and civic leaders is leading to a grass-roots restructuring of local environments to be conducive to health and well-being. Once empowered with data about the progress of their communities in creating healthy and sustainable environments, community leaders can begin to draw attention to the policy decisions that will help overcome negative health influences. Whether that will be in identifying pockets of unhealthy pollution through participatory sensing or in exposing unhealthy eating establishments through consumer blogs, some communities are using aspects of Web 2.0 technologies to gain a better understanding of the factors that lead to their own community's health.

We noted the evolution of the Internet and its influence the culture of science. Contributing data into a common, interconnected pool of analytic resources will help scientists begin to tackle the larger, more intractable problems in health.(B. Shneiderman, 2008) Just as it took thousands of scientists contributing to the common goal of documenting the human genome, it is reasonable to assume that it will take thousands more to unravel the mysteries of the genome for personalized medicine.

We also acknowledged the difficulties of getting scientists to work together across disciplines. The pressures of in-group and out-group divisions between the disciplines will make it difficult to bridge analyses with common measures, while the incentives of laboratory-based research environments will continue to reward individual achievement rather than group-based achievement. Nevertheless, there are projects aimed at using the architectures of Web 2.0 to highlight a "third way" between individually oriented and isolated science on the one hand and highly coordinated, but expensive "team science" on the other. Executed correctly, the third way should allow individual scientists to "plug and play" into the broader framework.(Buetow, 2005; B. W. Hesse, 2008)

Finally, we looked at online communities of practice to determine whether it would be possible to enhance the collective intelligence of the practitioner community. We identified ways in which the participative Web could benefit medical practitioners. Professionals can go online before a procedure to query the virtual community for tips on execution. Responses to the query might include video representations of the procedure to help enhance procedural knowledge, as well as tips on adapting the protocol to fit within a local context, or in providing real time feedback on unexpected consequences. In short, the sites could help with the implementation of efficacious practice. For such sites to work there must be credibility. Sites that mask the credentials of their contributors stand the risk of inciting the "cult of the amateur" and of distracting the practitioner from implementing high quality, evidence-based protocols.

In all of these examples, we became cognizant that the design of Web 2.0 sites will have a lot of bearing on whether the site contributes to greater collective intelligence or not. (Gregg, 2010) Indeed, in the polarized environs of the political blogosphere, the thrust of the discourse seems to be away from the wisdom of crowds and toward enhanced discrimination of elements of quality in content presented. Research dollars and meticulous attention should be expended to understand the best formula for creating sites that represent an accurate portrayal of a community's collective intelligence, rather than the biased expression of fringe members' hyperbole. Fortunately, the spirit of Web 2.0 is in rapid prototyping. One of the most important streams of data to protect is feedback on the system's own performance. The sites that will dynamically outperform all others are those that use data from the crowd judiciously to improve their own quality and performance over time.(Gregg, 2010; O'Reilly, 2005)

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