Implications of Internet Availability of Genomic Information for Public Health Practice

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Abstract

Tensions in the field have emerged over how best to communicate to the public about genomic discoveries in an era of direct-to-consumer (DTC) DNA testing services available through the Internet. Concerns over what the psychological and behavioral response might be to a nuanced, multiplex risk message have spurred some to offer caution in communicating to the public about personalized risk until the necessary research has been completed on how to communicate effectively. The popularization of DTC testing services, along with a spreading Internet culture on transparency for personal data, may make ‘waiting to communicate’ a moot point. To steer communication efforts in the midst of increasing access to personal genomic information, a self-regulation framework is presented. The framework emphasizes the importance of presenting a coherent message in all communications about public health genomics. Coherence should be based on an evidence-based model of how the public processes information about health conditions and an emphasis on risk-to-action links. Recommendations from the

President’s Council of Advisors for Science and Technology are reviewed as a way of identifying targets of opportunity for structured communications both within the healthcare system and in the broader external ecosystem of publicly available health information technologies.

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Tensions in the Field

A study published in the *Journal of Health Psychology* in 2009 illustrates a tension that has been building in the field of public health genomics over the past decade [1]. At issue is what to do in communicating the science of genomics research to the general public when the links between specific genetic variants and patterns of disease are poorly understood and probabilistic [2–6]. The problem is amplified by characteristics of a rapidly changing communication environment in which genomics-related stories and direct-to-consumer (DTC) genetic testing services are allowed to proliferate through new media channels in largely unfettered ways. The questions have to do with understanding, from a behavioral perspective, what the average consumer will do when learning about a link between some aspect of their genetic makeup and

a specific disease process [2]. Upon learning such information, will consumers infer an inappropriate sense of determinism and consequently refrain from engaging in risk-reductive behaviors related to that process [3]? For example, if consumers learn that the tendency to over-produce cholesterol (e.g. hypercholesterolemia or hyperlipidemia) is genetically predisposed in some people, but not in others, will those same consumers infer an inappropriate sense of invulnerability for themselves and thus give up on their own intentions to modify their diets?

To address the question, the study's authors exposed participants to simulated news reports describing the general link between genetic factors and salt sensitivity in 1 set of studies (studies 1a and 1b) and genetic factors and heightened cholesterol production in another (study 2). Participants' awareness of these factors was assessed ahead of time, with a general assumption that those who were unaware of these links would show a greater effect from the news stories than those who already knew about them. That is, the presentation of a news story explaining that some people are at greater risk for certain ailments than others would lower a sense of pervasive danger within the general population; and, in the absence of personal risk information, may dissuade people from modifying their own personal behaviors until they gained further understanding. Following the investigators' predictions, those who were unaware of the links beforehand *were more likely* to report lower perceptions of risk and decreased intentions to modify diet than those who were already aware of those links. With these results in-hand, the authors concluded: 'We are thus in dire need of more empirical research on this matter before informing the general public about the existence of genetic risk factors, and especially before deciding on a specific strategy to do so' [1].

This cautionary conclusion – that genetic risk information should not be communicated to individuals or the public until more conclusive research has been conducted – stands in stark contrast to the world of DTC genetic testing promulgated broadly through the Internet. In general, the ethos within 'the Culture of the Internet' [7] is one of transparency. Born from the counterculture of the 1960's and 1970's, the motivating principles underlying the personal computing revolution of the 1980's and the online Internet revolution of the 1990's were based on the concept that 'information is power' and that gaining free and open access to information is a desirable end [8]. There is some indication that the public has begun to embrace that ethos with respect to health information and has grown accustomed to searching for, and utilizing,

online health information in substantial numbers [9]. The question is: what might the implications be of creating unfettered access to the nuanced, technically sophisticated, sometimes conflicting, occasionally wrong, and probabilistic information of DTC genetic tests for consumer health?

A Natural Experiment

Philosophical tensions aside, the public has been engaged in a natural experiment over the past 2 decades in which data and information about health have been made broadly accessible through networking and information technologies. In this sense, the debate over *whether* to keep communications about genetic risk factors over the Internet at bay until more scientific studies have been conducted has largely been made moot. A systematic review reported that there were 27 different online, DTC testing companies in 2007 [10]. Patient advocates have since been lobbying for greater access to data about their physiologic functions, from quantified measures of daily metabolism to personalized assessments of genetic predilections [11]. In a 2011 conference on 'Open Government' hosted at the US National Archives, a biostatistician explained that rather than being put off by difficult-to-understand statistics about their care and treatment, many patients are arguing for access to their own data as a 'civil right' [12]. Patient advocates have summarized their sentiments about sharing data for care or research with the slogan 'no data about me without me' [11].

Diffusion of Online Health Information

What, then, have the results been of this natural experiment in open data access? In 1999, the estimated number of adults using the Internet in the US lingered at around 37% of the total population [13]. Internet penetration among adults climbed to 63% by 2003 [14] followed by estimates of 68% in 2008 [15] and 78% in 2010 [13]. In 2005, an estimated 76,502,088 people went online to look for health information for themselves or their loved ones [14]. Of those who went online in 2008, about a quarter – or 33,973,131 adults – reported talking about what they found online with their doctor or other health professional. In 2008, roughly 14.4% of those online (22,114,887) reported buying medicine or vitamins online; 13.5% reported using e-mail to communicate with their doctor or doctor's office; and 4.9% (7,584,731) participated in an online support group with people having similar health or medical conditions [15]. In 2008, an estimated 29.2%

of American adults – or 64,300,922 people – reported having heard or read about tests ‘marketed by companies directly to consumers’ to assess ‘DNA, diet and life-style for potential risks.’ An estimated 8.1% of American adults – or 5,245,012 people – in the same survey said that they had taken such a test.

On the supply side, the total number of websites available to the public climbed from a meager 130 reported in June of 1993, to 2,410,067 in 1999 and then grew exponentially to over 250,000,000 by July of 2010 [16]. The number of references accumulated when entering in the specific pharmaceutical term ‘Femara’ (an aromatase inhibitor used in the treatment of breast cancer) on the open Web in 2001 was 1,060 [17], while the same search yielded 1,730,000 references in 2009 and 7,100,000 in 2011. Daily e-mail traffic rose from 12 billion in 2000 to 247 billion in 2010; active blogs rose from 12,000 in 2000 to 141 million in 2010; and daily Google® searches rose from 100 million in 2000 to 2 billion in 2010 [18].

Although discussion groups and chat rooms were around in 1999, many observers could not have foreseen the rise of social participation websites that would lead some to declare an evolution from Web 1.0 to Web 2.0 [19, 20]. Through the participative environs of Web 2.0, persons diagnosed with serious disease could share their stories in video through YouTube [21]; form networks of support around them through Facebook® [22], Caring-Bridge® [23] and Twitter® [24]; and even seek out similarly diagnosed others for sharing data on treatments through PatientsLikeMe® [19]. Nor could they have foreseen a circumstance in which thousands of consumers would willingly pay money to order a cheek swabbing kit from the online DTC genomic company ‘23AndMe®’ and then contribute data from the genetic analysis of their samples to replicate an NIH-funded study that originally took 6 years to complete, cutting the completion time down to 8 months [25].

Risks and Cautions

As Internet usage spreads, a number of panels and authors offered warnings on what some of the negative consequences of accessing online health information might be. Among some of the concerns expressed were worries that: (a) information of dubious quality might cause malevolent effects [26, 27], (b) that too much information available online might cause a sense of escalating confusion [28–30] and (c) that the availability of alternative sources of credible medical information might erode patients’ trust in physicians [28, 31].

What about these negative forecasts? Have they materialized to the degree cautioned by many of these early commentaries? Here, the evidence is mixed. The prevalence of questionable websites, foisting unfounded remedies and offering seemingly objective evidence as a mask for ulterior profit motives, has undoubtedly increased along with the general growth of the Web [32]. By moving facilely beyond borders, companies have used loopholes in international eCommerce to get around domestic restrictions in selling cigarette products to minors [33] and prescription drugs to those without a physician’s approval [34, 35]. Online networks have produced new types of fraud and predatory consumer practices (e.g. ‘phishing’, ‘bot-nets’ and pump-and-dump securities schemes). Because of the rapidity associated with online social networks, health myths can now ‘go viral,’ disseminating just as quickly as any evidence-based health finding [36].

In spite of the proliferating opportunities for deception, however, the public has shown some degree of resilience when it comes to dealing with misleading health information on the Web [37, 38]. Stories of patients who abandon their physicians’ advice to follow the dangerous exhortations of consumer-oriented websites are rare and are no more prevalent than in offline conversations. In fact, there might be some evidence to suggest that under certain conditions the connective properties of online media may serve to combat the problems of information isolation often experienced by those struggling with health problems on their own. When someone hears of a questionable health suggestion (e.g. smoking is a good way to lose weight), they can go online and check that supposition out against the collective conclusions of others like themselves [39]. Similarly, stories abound of people who may have encountered a potential symptom and were unsure of what to do about it, but by exploiting the strength of ‘weak ties’ on the Web were able to get informational support on what to do [22, 40, 41]. Getting a second opinion, and even a third or fourth opinion, through online discussion groups can help patients triangulate on the best therapeutic choices to discuss with their care teams, whereas those who find themselves isolated offline must struggle with a limited number of (often uninformed) opinions from friends or family [41, 42].

What may be missing in the unregulated environs of the Web, though, is careful attention to the interpretative information that patients may need to make sense of the cacophony of data available in a rapidly changing and highly populated information environment. Data from the Health Information National Trends Survey suggest that confusion over the causes and clear paths for preven-

Fig. 1. Using the Common Sense Model of Disease to create coherence between risk messages (genetic susceptibility) and action plans (behavior): Adapted from Cameron and Leventhal (2003) *The Self-Regulation of Health and Illness Behaviour*, p 50.

tion against such complex genetic diseases such as cancer is increasing. Results portrayed a 7.7% increase in the already high percentage of people who strongly or somewhat agreed with the statement that ‘it seems almost everything causes cancer’ from 2003–2005 and a 3.7% increase in the already substantial number of people who agreed with the statement that ‘there are so many recommendations about preventing cancer it’s hard to know which ones to follow’ [43]. In a social media (i.e. Facebook) survey of the public’s opinions regarding DTC genetic test results, researchers found that the general public tended to believe that the probabilistic results of DTC tests would be more useful than did genetic counselors. The investigators concluded that more research would be needed to provide DTC test results in ways that minimize risk of misinterpretation by consumers [44].

This trend of seeking the input of others to improve decision-making does not necessarily mean that patients are using online networks to replace the professional council of their doctors; in fact, just the opposite may be true. Data from the Health Information National Trends Survey showed *increasing levels* of trust in their medical teams and at the same time that levels of Internet usage as a source of first resort for health information were climbing [15, 45]. These data suggest that the ways in which information technology is insinuating

itself within the professional-consumer relationship is different in medicine than it is in other industries, such as travel. In other industries, customers ‘cut out the middleman’ to go straight to the source for buying products and services, a term referred to as disintermediation. Within health care, both patients and their care teams are constantly being surrounded by new information in health. Both sides appear to be working together to make sense of the burgeoning information explosion, with professionals bringing experience and education and patients bringing their values and self-knowledge to the encounter [46]. In this new environment, consumers may still need a clear path to medical professionals in order to interpret the findings of online health information [47, 48].

Building a Framework for Reducing Uncertainty

To understand how to reduce uncertainty regarding the findings of genomic tests promulgated through the Web, it is useful to consider the ways in which people process information about disease and health conditions. One useful model that can serve as a guide is the common sense model of disease introduced by Cameron and Leventhal [49] as depicted in figure 1. According to

this basic information processing model, individuals are exposed to informational stimuli both from the external environment (e.g. DNA analyses of endogenous vulnerability) and from the internal, cognitive environment (e.g. contemplating, synthesizing and processing for 'gist'). Individuals use that information to derive coping strategies for perceived threats. This particular framework is referred to as a 'dual process' model because it acknowledges that neural stimuli are likely to trigger parallel processes, both down a highly automatic, affect-laden path and a more rational, action-oriented path. A key to successful communication based on the model is the importance of providing a clear risk-to-action link so that individuals can adopt adaptive coping strategies. If that 'safety information' is not given, and the individual is incapable of addressing the health threat with action, they may resort instead to resolving their own internal tensions psychologically. They may feel paralyzed and confused as to what to do. As a consequence, they may seek to avoid future communications on similar subjects or simply rationalize their own lack of precaution [49, 50].

Cameron and Leventhal [49] have also been successful in understanding how consumers think about the process of disease. In the top part of figure 1, above the dashed line, is a representation of the cognitive schemata [51] (or mental model) that most people follow when interpreting information about health conditions. Quite commonly they look first to give the condition-in-question a name (e.g. risk for high cholesterol). They then seek to understand the timeline and temporal qualities of the condition. Is this an acute condition or a chronic condition? Does the condition require immediate attention now or does it simply require an attitude of watchful waiting? Most people also want to know what might be causing the condition and, in very related way, what that means for creating an action plan for controlling the risk. Here, the delicate balance between endogenous and exogenous factors becomes important. To what degree is the condition inherited, and if it is inherited can something be done to cope with the risk perhaps through chemoprevention, behavioral modifications or routine screening? Some risks cannot be controlled, and if that is the case then people need to know that so they can adjust their psychological appraisals appropriately. Studies suggest that long-term understanding can be improved and adaptive health behaviors can be nurtured by delivering information in a way that conforms to this common sense model of disease [49, 52–54].

A study by Cameron et al. [55] illustrates how the self-regulation model can be used to evaluate Internet-based presentations of genetic risk information. In an Internet-based experiment across 4 countries, the team evaluated responses from 749 adults to messages about a hypothetical test for colon cancer risk. Messages varied by risk-action link information, in this case the provision or no provision of information on how a low-fat diet would reduce risk given the presence of a positive result on the hypothetical genetic test. According to their results, providing risk-action link information appeared to improve participants' coherent understanding of the disease process, it improved their sense of response efficacy (faith that behavioral action will reduce the risk), and it lowered appraisals of anticipated risk given positive results on the hypothetical test.

Implications for Public Health Practice

Within the context of an emerging health information ecosystem, should public health practitioners take precautions to protect consumers from some types of DTC genetic information? In one sense, the answer is an emphatic 'yes'. Anytime a biotechnology firm advertises a product that purports to give information on personal physiologic conditions, the veracity of those claims should be open to verification through government oversight or consumer group vigilance [56]. Misrepresented claims or shoddy assessments should be brought to the attention of the appropriate boards and regulatory bodies to correct for informational malpractice. More broadly, the public health agenda should continue the pursuit of a credible and reliable scientific evidence base to undergird productive use of genomic technologies in medicine and beyond [57].

The real challenge, though, may not lie in excluding personal genetic information from online information seekers prematurely, but in creating better informational resources for improving consumer understanding [58]. As explained by a previous director of the National Institutes of Health to members of Congress, medicine in the 21st Century is geared toward creating a public health environment that is increasingly more predictive, preemptive, personalized, and participative [59–61]. Empowering patients with a clear and evidence-based understanding of their own individualized risk profiles, and then supporting healthy decision-making over the lifespan in consultation with medical professionals, is fully consistent with recommendations for quality im-

provement and cost reductions in healthcare offered by the Institute of Medicine [62, 63]. Using a public health framework for communication that will give patients a better understanding of the probabilistic processes guiding their own health, while providing them with the predictive data and coherent courses of action to self-regulate behavior, lies at the heart of recommendations for patient-centric reform in healthcare and science [17, 64–66].

Improving Communication within Healthcare

In December 2010, the US President's Council of Advisors of Science and Technology delivered 2 reports relevant to the task of creating a more supportive information environment for the public and for patients. The first one, titled '*Realizing the Full Potential of Health Information Technology to Improve Healthcare for Americans: The Path Forward*' [67], provided technical detail to the national task of infusing healthcare with reliable information systems to support better care. The report built on the Congressional mandate for building healthcare systems that are safe and effective, engaging to patients, continuous across providers, supportive of population health, and secure. Within this idealized environment are a number of opportunities for building the safeguards needed to optimize consumers' understanding of genetic risk. For example, efforts are underway to incorporate genetic risk information within the standard reporting capacity of electronic health records. Health systems are creating their own web-based portals to an individual's electronic health records data, referred to as a tethered Personal Health Record system. In this context, every interface has the potential of serving as a communication intervention: that is, in providing the standardized presentation of genetic risk information to both the clinical team and the patient that conforms to best practice in human factors research and user-centered design. Record keeping systems and built-in communication channels (e.g. through secure e-mail) can also serve to bring patients in reliable contact with the genetic counselors, primary and specialty care physicians, nurses, and other team members to resolve confusion.

Improving Communication through the Open Internet

The other report, titled '*Designing a Digital Future: Federally Funded Research and Development in Networking and Information Technology*' [68], focused on the evolution of Internet-based technologies outside of the healthcare system. This report emphasized the interactive and socially connective nature of the evolving infor-

mation environment outside of healthcare and suggested that new research be conducted to 'enable both professionals and the public to obtain and act on health knowledge from diverse and varied sources as part of an interoperable health IT ecosystem.' An important theme in this regard is the recognition that the public information environment is evolving beyond a one-way, mass medium model only, to a 'many-to-many' Internet-mediated environment for shared understanding. Research conducted by Cappella [69] within an NCI-funded Center of Excellence on Cancer Communication Research, for example, demonstrated that it is possible to improve the presentation of genetic discovery to the public by linking reporters directly with scientists. Recognizing that traditional news environments are rapidly evolving to take full advantage of online communication channels, it is possible to envision a system that could help improve public health reporting in genomic science. It is also possible to envision advanced networking and information technology techniques that could help citizens participate more directly in the advancement of scientific knowledge [70, 71].

Conclusion

By all indications, the fields of medicine and public health are at a serious inflection point. The strengths of industrial age medicine, with an emphasis on mass-produced 'one-size-fits-all' treatments applied late in the pathological progress of disease, are turning into financial and biological liabilities. The field of public health, which has been struggling to define its boundaries in a rapidly changing context of policy change and community self-organizing, is gearing up to deal with the consequences of globally spreading chronic disease. Innovation is needed to ensure that the petabytes of data being produced by improved cost-efficiencies within the gene sequencing industry are marshaled for discovery and public health translation. As genomic pioneer Venter [66] declared, patients – equipped with cutting edge access to their own DNA – may soon be the co-creators of biomedical discovery within wholly new public health environments. Without attending to the psychosocial consequences of communicating genetic information effectively within these new environments, however, that opportunity may only give way to escalating confusion.

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