Big Desire to Share Big Health Data: A Shift in Consumer Attitudes toward Personal Health Information

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Abstract

Sharing personal health information is essential to create next generation healthcare services. To realize preventive and personalized medicine, large numbers of consumers must pool health information to create datasets that can be analyzed for wellness and disease trends. Incorporating this information will not only empower consumers, but also enable health systems to improve patient care. To date, consumers have been reluctant to share personal health information for a variety of reasons, but attitudes are shifting. Results from an online survey demonstrate a strong willingness to share health information for research purposes. Building on these results, the authors present a framework to increase health information sharing based on trust, motivation, community, and informed consent.

Introduction

Consumer attitudes toward sharing personal information are changing. A recent Businessweek article about consumer privacy issues stated, "Given the choice between pizza and privacy, a remarkable number will opt for the pizza." (Brady 2013). Translating those incentives to improve healthcare remains an ongoing challenge. Globally, healthcare is regionalized, populations are aging, and individuals are increasingly more educated about healthcare issues. Additionally, U.S.-based consumers are seeking pricing transparency to purchase value-based, rather than fee-based healthcare. To respond to these changing requirements, personal health information sharing can provide an important component to facilitate next generation health services. This study explores personal health information sharing, which can occur in at least three venues: 1) health information sharing between health agencies, 2) individuals sharing health data with medical providers, and 3) individuals sharing health data in

health research studies, health social networks, biobanks, and nationwide health information exchanges.

The benefits of information sharing between health agencies have been documented. For example, the Premier healthcare alliance claims that sharing outcomes data saved 92,000 lives and $9 billion over the four and a half year study period. Nationwide, hospitals could save a projected 950,000 lives and $93 billion over a five year period (Monegain 2013). In the U.S., federally-sponsored programs are underway to develop an interoperable data infrastructure to link health providers nationally (McKinney 2013; U.S. Department of Health and Human Services 2013). Some ratios, such as the percentage of patients who have ceased using tobacco, had childhood immunizations, or received nutrition counseling are gathered and shared with the Centers for Medicare and Medicaid Services. These population health measures are designed to improve healthcare for providers, but do little to improve the health of the individual (CMS 2013). Individuals can be particular about which data they would like to share with whom and under what circumstances. A 2010 survey showed that a majority of adults expressed discomfort (42%) or uncertainty (25%) if their anonymized health information were shared with other organizations (California HealthCare Foundation 2010). In June 2013, an InfoSys survey showed that only 58% of U.S.-based respondents were willing to share personal or family medical history with healthcare professionals (InfoSys 2013). Other surveys have found that consumers are more willing to share health data. In a March 2013 survey, Cisco found that 74% of consumers were willing to participate in remote health services and cloud-based storage of their personal health data (Horowitz 2013). Sharing health

information is acknowledged to be more complex than in other areas such as consumer spending and financial data, where similar privacy concerns exist (Agarwal and Anderson 2008; Balaram et al. 2013).

A number of Web sites and online communities based on research goals have had greater success. For example, in one study of controlled health record users, 91% were willing to share medical information for health research purposes, with 59% preferring an opt-in sharing model (Weitzman, Kaci, and Mandl 2010; Weitzman et al. 2012). At 23andMe, 87% of all customers have agreed to participate in research, and 88% have answered at least one research question (Tung et al. 2011). New models of participant-centered sharing suggest that sharing is more likely to occur when individuals have the power to select the conditions under which they share (Kaye et al. 2012).

The advent of personal genomic services in 2007 has provided a unique venue for studying personal attitudes towards information sharing. Although current FDA regulations have slowed the adoption of direct-to-consumer approaches in the U.S., consumers have had the increasing ability to obtain, use, and share their own health information (FDA 2013). One study found that consumers had a positive attitude towards consumer genomics; they purchased services related to medical care and were willing to share results with physicians for interpretation (McGuire et al. 2009). Another study found early users approached personal genomics with both optimism for genomic research and skepticism about the technology's capabilities (McGowan, Fishman, and Lambrix 2010). A more recent study examined personalized genomic medicine based on individualized risk diagnosis and prevention, and explored how outcomes could be improved as our understanding of health and preventive wellness expands from medical to social contexts. (Juengst et al. 2012). A final, emerging dimension for health information sharing is its importance not only for health outcomes, but also for its societal effects in destigmatizing health issues (Swan 2013; Kido and Swan 2013).

Description and Methods

The objective of this study was to investigate consumer attitudes toward sharing health information, particularly for research purposes. Two key questions guided the online survey developed for this research:

1. Are consumers willing to share genomic, medical and health tracking information for research purposes?

2. Do consumers have interest in receiving recommendations based on shared personal health information?

Other questions attempted to gauge consumers' willingness to share; what data types they were willing to share; whether physicians influence the sharing process; who should control access and review of data; what consumers want to know after sharing; why they share; what they see as risks and benefits; and what barriers may exist to limit sharing.

The study was conducted by recruiting crowdsourced health study cohorts. Enrollment was open and ongoing, with a minimum of 100 participants sought for the first phase of data analysis. Study recruitment and operation was performed via the Internet-based health collaboration community Genomera (www.genomera.com). The survey was hosted by Traitwise (www.traitwise.com), a company that provides gamification-enhanced surveys to increase participant engagement.

Before gathering data, the survey instrument was posted on Genomera for a two week open review period. In addition, participants were able to comment and post questions throughout the duration of the survey. To access the survey on the Genomera site, participants were first consented via an online form (http://bit.ly/sharing-health-info-consent), which was overseen by the RIKEN GENESIS Institutional Review Board (www.rikengenesis.jp). After consent, participants were directed to the Traitwise-hosted survey. Since Genomera is in a limited release beta period, the consent form was also added to the Traitwise survey to increase participation. The survey received 40 responses from Genomera participants (http://www.genomera.com/studies/sharing-health-information), and 88 responses directly from Traitwise (http://bit.ly/sharing-health-info-survey). In all cases, participants were consented.

The inclusion criteria were a willingness to participate and self-declaration to be at least 18 years of age. In a small number of cases, participants' responses were excluded because they did not agree to the consent form (n=3), or when the number of responses was one or zero (n=10). After excluding disqualified participants, responses from 128 participants remained. All responses are anonymous

and not personally identifiable. To reduce order bias, survey questions were presented randomly, and respondents had the option to skip any question.

Results

During the survey timeframe of July 30, 2012 to April 30, 2013, 128 participants provided over 7,900 data points. The 27-question survey produced a maximum of 91 responses per person. The average number of responses was 71 and the median was 89. In the top quintile (73-91 responses), 73% of respondents answered 73 or more questions (Figures 1 and 2). The average time to complete the survey was five minutes.

Demographics

Although the majority of respondents self-reported to be from the United States (72%), more than 12 countries were represented (by region: North America (77%), Europe (14%), Australia (4%), Asia (1%), other (5%)) (Figure 3). In the U.S., the majority of respondents were employed full-time (55%) or self-employed (19%), reflecting somewhat higher rates of employment than the U.S. average [ref] (Figure 4). Most respondents had completed at least four years of college (86%), with 59% of respondents reporting a Master's level education or higher. For U.S.-based participants, education rates were similar (84% and 54%, respectively) (Figure 5). Top areas of employment were computing/IT (21%) and science/research (21%) (Figure 6).

The gender of the respondents was reported as 50% female and 50% male (Figure 7). Age cohorts were banded in 5-year increments from 20 to 90+ years. Age cohorts between 20 to 74 years received at least two responses in each age band, and the 90+ cohort received one response. The average age cohort was 40-44 years, and the pseudo median was 41 years (Figure 8).

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Willingness to share

Six questions explored participants' willingness to share health information. The question "I am willing to share my health and medical information" received 105 responses: 63% were willing to share personal information "in some cases," and approximately one-third responded "yes" (Figure 9). A response of "in some cases" or "yes" prompted five additional questions about data sharing, presented to respondents in random order. The first question asked with whom respondents were willing to share health and medical information: personal physician or healthcare provider (88%), non-profit research organizations (84%), family member (83%), universities or academic institution (79%), government (28%), for-profit companies (24%), others (23%), insurance companies (14%) (Figure 10). The second question inquired about the motivation for sharing health information: make new health discoveries (88%), learn more about personal health risks (82%), desire to change current system (73%), health condition (66%), learn more about my ancestry (31%), want something in return (15%), bragging rights (11%) (Figure 11). The third question queried what respondents would like to know based on the information shared: actionable things I can do to improve my health (93%), my likelihood to develop a disease (86%), what others like me are doing to stay healthy (82%), my current state of health (81%), my health relative to peers or others (71%), how my health may affect my children (62%), other (17%) (Figure 12). Question number four asked whether respondents would like to connect with others who have similar health conditions: yes (70%), no (30%) (Figure 13). The last posed whether or not respondents would share information even if it were not anonymized: in some cases (68%), no (19%), yes (13%) (Figure 14).

Finally, all respondents were asked two questions about sharing irreversibly anonymized information for research purposes. If data were irreversibly anonymized, 71% of respondents were willing to share data with researchers: yes (71%), in some cases (21%), no (2%) (Figure 15). In a related question, one-third of respondents were not concerned, and about half are either concerned or very concerned about the re-identification of their anonymized health and medical information (Figure 16).

What to share

When asked about sharing health and medical information, participants responded that they would share these data

"under the right circumstances": diet (88%), exercise (88%), traits (85%), diseases and conditions (81%), and genomic data (80%), fitness tracking information (80%), medications (79%), environmental factors (78%), electronic medical records (72%), other (27%). The respondents' average "willingness to share" across the data types surveyed was 76% (Figure 17). Almost two-thirds (64%) of respondents declared owning one or more tracking devices: Fitbit or other activity tracking (28%), blood pressure cuff (27%), wireless scale (17%), blood glucose monitor (16%), Zeo or other sleep monitoring device (12%), other (18%) (Figures 18 and 19). Approximately one-third (34%) of respondents reported being genotyped by a company such as 23andMe, Navigenics, Pathway Genomics, etc.: no (66%), yes (34%) (Figure 20).

Influencers

Two questions explored the physician's role in data sharing. In the first, respondents were asked a sliding scale question about the perception of their physician, from "Godlike" to "just another person." Over half of respondents in the top quintile (56%) saw their doctor as "just another person" (Figure 21). A second question inquired whether sharing might be influenced by physicians. Most respondents were indifferent if their physicians were to tell them it was safe to share health and medical information; however, about thirty percent were more likely to share if their physicians told them it was safe to do so (Figure 22).

Access and review

When asked who should control access to anonymized medical data for research purposes, respondents responded: myself (69%), non-profit organizations (45%), universities and academic institutions (38%), national databanks (34%), government (25%), for-profit companies (6%), insurance companies (3%) (Figure 23). After uploading health and medical information, respondents stated a willingness to pay various entities to review data and provide recommendations: non-profit organization with recommendations based on scientifically validated algorithms (63%), physician or healthcare provider (59%), genetic counselor (52%), for-profit company with recommendations based on scientifically validated algorithms (40%) (Figure 24).

Sharing and motivation

Based on information shared, respondents wanted to know: actionable things I can do to improve my health (93%), my likelihood to develop a disease (86%), what others like me are doing to stay healthy (82%), my current state of health (81%), my health relative to peers or others (71%), how my health may affect my children (62%), other (17%) (Figure 12). After sharing health and medical information, 70% of respondents would like to connect with others who have similar health conditions (Figure 13). The majority of respondents are more likely to share if they receive personalized recommendations based on discoveries made from their data (53% in top quintile) (Figure 25). Conversely, when asked about being more likely or less likely to share health and medical information in return for money, about one-quarter of respondents would be less motivated, and one quarter would be more motivated: bottom quintile (22%), middle quintile (36%), top quintile (25%) (Figure 26).

Risk/benefit and barriers

Concerning the risk and benefit of sharing health information, 58% of respondents answered that contributing health and medical information to medical research is "a little risky, but potentially or very beneficial" (Figure 27). Two-thirds of respondents also believe it would improve healthcare "absolutely" if people would be willing to provide their health data (Figure 28). Responses to perceived barriers to sharing health information include: privacy concerns (85%), lack of awareness of value of contribution (77%), concern about data being used for profit (58%), no easy way to share data (45%), other (13%) (Figure 29). When asked about sharing genomic data, specific sharing concerns included: insurance discrimination (67%), personal or family privacy (43%), employment discrimination (40%), racial discrimination (11%), other (20%) (Figure 30).

Discussion and Limitations

This section discusses a number of limitations of the study, and highlights several general themes. Regarding the survey instrument, over 70% of participants responded to more than 90% of all survey questions. The high survey response rate can in part be attributed to the self-selected nature of the participants. Increased survey engagement may also be the result of the Traitwise survey platform,

which encourages continued participation by providing respondents with immediate feedback after each response (Figure 31). A second phase of the survey is underway to analyze the effectiveness of the Traitwise platform relative to traditional survey instruments. A number of known limitations exist surrounding the use of self-reported data (Swan 2012, 2012a, 2013). The greatest limitation of the study is that the number of respondents is relatively small (n=128). Cohort-based correlations were not possible due to the small number of responses in each age group (n<20 for all groups). Finally, with 54% of U.S.-based participants reporting at least a master's level education, the respondent's education level is more than four times higher than the U.S. average (U.S. Census Bureau 2012). Generalizing these results requires additional research across a broader population with more diverse educational backgrounds. To continue validating results, the study has been re-opened on Genomera to gather further survey data (http://www.genomera.com/studies/sharing-health-information). In addition to these limitations, a number of general themes emerged that may influence how and when consumers share health information, discussed below.

Privacy Paradox

The idea that consumers are worried about their privacy, but choose to disclose information despite their reservations has been called the privacy paradox. Acquisti et al present evidence that privacy concerns follow a U-shaped distribution that cluster around extreme focal points (Acquisti, John, and Loewenstein 2010). Although some researchers believe that a growing privacy movement will require stricter controls (Lewis, Kaufman, and Christakis 2008), privacy preference research in social network sites shows that consumers become more relaxed with sharing over time (Barnes 2006; Utz and Kramer 2009). The results from this study indicate a high willingness to share health information with physicians, family members, and non-profit research institutions, despite privacy concerns. The desire to share health information for research purposes is especially strong when the data are irreversibly anonymized, although privacy in this area cannot be guaranteed (Gymrek et al. 2013).

Access Controls

In science, the issue of access versus ownership has a rich history (Hilgartner and Brandt-Rauf 1994; Kent 1999). Contemporary discussions surrounding healthcare information are about information access rather than

ownership (Trotter 2012). In this survey, over two-thirds of respondents indicated a personal desire to control access to their anonymized health information with researchers, suggesting that active monitoring, opt-in, or policy-based control systems will be required (Kaye 2012). How these data access controls will evolve is uncertain, although Meaningful Use standards in the U.S. will certainly play a role (CMS 2014).

Health Data Commons

A very practical concern is the lack of a health data commons, that is, data storage location(s) for personal health information (Swan 2013). Many initiatives are underway to address this issue, including public research repositories such as Coriell Personalized Medicine Collaborative, DNA Digest, Genomes Unzipped, openSNP, Personal Genome Project, Reg4All, and Sage Bionetworks. Consumers may also benefit from the recently proposed Patient Generated Health Data model from the HL7 standards committee (HL7 Standard Committee 2014). Rare disease and pre-competitive registries provide similar data services, but on a more focused level (Sanford 2014, Cancer Commons 2014, TranSMART 2014). Similarly, for-profit concerns such as 23andMe and PatientsLikeMe have business models that include the sale of aggregated and anonymized data to pharmaceutical and other healthcare concerns. To address data interoperability, academic-based consortiums and government-backed initiatives are exploring standards for sharing genomic and phenotypic data (eMerge Network 2014; International Cancer Genomics Consortium 2014; Genome Standards Consortium 2014; Phenx.org 2014). These health data repositories are developing independently and incorporate vastly different economic models. Standards and federated sharing models will be essential to create datasets that can be shared and analyzed for wellness and disease trends.

Motivation / Value Proposition

For participants, the motivation to share was largely driven by a desire to make new health discoveries and learn about personal health risks. Monetizing the sharing process produced an ambivalent result, leading to the possibility that many of the participants could be thought of as data altruists (Kohane and Altman 2005). If true, health data shared by relatively few individuals could produce results for many. In return for sharing, participants were interested in actionable suggestions to improve their health, their

likelihood to develop a disease, and a social reciprocity regarding what similar participants were doing to stay healthy. A majority would like to connect with others with similar conditions, suggesting that the social value of sharing should not be overlooked.

Recommendations based on shared information

In this population, respondents most often reported a willingness to pay non-profit organizations and physicians to review and provide recommendations based on the results of their shared health information. Commercial solutions such as the Understanding Your Genome service from Illumina, coupled with the company's recent announcement of a high-end sequencer that can deliver the long sought-after $1000 genome, portends a market for these services. Health coaches, physicians, and social health sites will all be candidates for the future of personalized health recommendations (Swan 2012a).

A Framework to Increase Health Information Sharing

Based on the results of this survey, we propose that health information sharing can be increased by focusing on the following areas: trust, motivation, community, and informed consent (Figure 32). Trust addresses previously discussed access control issues; motivation explains consumer eagerness and willingness to share; community incorporates social aspects of sharing; and informed consent such as Portable Legal Consent provides the legal constructs necessary to safeguard privacy (Portable Legal Consent 2014). Taken together, this framework can advance participant-centric initiatives and create sustainable research partnerships.

Conclusions

Sharing health information is critical to the realization of personalized and preventive medicine. Key challenges include the formation of nationwide health information exchanges and biobanks where individuals can contribute data from different healthcare providers. Permission-based data sharing will enable consumers to determine how and when health information will be used. Appropriate portable consent informs this process, and will unlock barriers to sharing health data within specific contexts. The results from this study indicate a strong willingness to share personal health information in the population surveyed. A

critical mass of consumers who are willing to share their health information will enable next generation healthcare services, ultimately leading to improved health outcomes for all.

Supplemental Information

1. Sharing-Health-Information-Questions.pdf – PDF document with survey questions and study overview

2. Informed-Consent-SHARING-HEALTH-INFORMATION.pdf – PDF document with study consent form

3. Sharing-Health-Information-Responses.csv – Comma-delimited file with all response data

4. Sharing-Health-Information-Analysis.xls – Microsoft Excel document with analysis data

5. Sharing-Health-Information-Figures.pdf – PDF document with all figures

Additional Information and Declarations

K. Thomas Pickard has no conflicts to declare. Melanie Swan is affiliated with two of the collaborative health organizations discussed, DIYgenomics and Genomera.

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References

Acquisti, A.; John, L.; and Loewenstein, G. 2010. What is Privacy Worth? 2010 Future of Privacy Forum's Best "Privacy Papers for Policy Makers" Competition.

Agarwal, R.; Anderson, C. 2008. The complexity of consumer willingness to disclose personal information: Unraveling health information privacy concerns. *eHealth Initiative's 5th Annual Conference*; Washington, DC.

Balaram, S. ; Dunn, T .; Harris, M.; Kohn, J. ; Le, H. ; Lee, C. ; Lieberman, O.; Lin, T., and Sachs, A. 2013. Studies on Understanding Individual Willingness to Disclose Genetic Information to Public and Private Stakeholders. Thesis. University of Maryland, College Park, MD.

Barnes, S. 2006. A privacy paradox: Social networking in the United States. *First Monday*. vol. 11, no. 9.

Brady, D. 2013. Privacy Paradox: Americans Happy to Share Personal Data With Big Business. *Businessweek* June 25, 2013.

California HealthCare Foundation. 2010. Survey. http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/P DF/C/PDF%20ConsumersHealthInfoTechnologyNationalSurvey. pdf

Cancer Commons. 2014. http://www.cancercommons.org

CMS. 2013. Additional Information Regarding EP Clinical Quality Measures for 2014 EHR Incentive Programs. http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/EP_M easuresTable_Posting_CQMs.pdf

CMS. 2014. EHR incentives. http://www.cms.gov/EHRIncentivePrograms

eMerge Network. 2014. http://www.genome.gov/27540473

FDA. 2013. Inspections, Compliance, Enforcement, and Criminal Investigations. 23andMe, Inc. November 22, 2013. http://www.fda.gov/iceci/enforcementactions/warningletters/2013 /ucm376296.htm

Genome Standards Consortium. 2014. http://gensc.org

Hilgartner, S.; Brandt-Rauf, S.I. 1994. Data Access, Ownership, and Control Toward Empirical Studies of Access Practices. *Science Communication* 15.4: 355-372.

HL7 Standards Committee. 2014. Patient Generated Health Data. http://www.hl7.org/implement/standards/product_brief.cfm?prod uct_id=316

International Cancer Genome Consortium. 2014. http://icgc.org

Gymrek, M.; McGuire, A.L.; Golan, D.; Halperin, E.; Erlich, Y. 2013. Identifying Personal Genomes by Surname Inference. *Science*. vol. 339 no. 6117 pp. 321-324. doi: 10.1126/science.1229566

Horowitz, B.T. 2013. Cisco Says 74 Percent of Consumers Open to Telehealth Sessions. *eWeek*.

http://www.eweek.com/networking/cisco-says-74-percent-of-consumers-open-to-telehealth-sessions/

InfoSys. 2013. Digital Consumer Study. http://www.infosys.com/digital-consumer-study

Juengst, E.T.; Settersten, R.A. Jr; Fishman, J.R.; McGowan, M.L. 2012. After the revolution? Ethical and social challenges in 'personalized genomic medicine'. *Per Med*. Jun 1;9(4):429-439.

Kaye, J.; Curren, L.; Anderson, N.; Edwards, K.; Fullerton, S.; Kanellopoulou, N.; Lund, D.; MacArthur, D.G.; Mascalzoni, D.; Shepherd, J.; Taylor, P.L.; Terry, S.F.; and Winter, S.F. 2012. From patients to partners: participant-centric initiatives in biomedical research *Nature Reviews Genetics*. doi:10.1038/nrg3218

Kent, A., ed. 1999. *Encyclopedia of Library and Information Sciences*. New York, NY: Marcel Dekker.

Kido, T.; Swan, M. 2013. The Potential Power of Personal Genomics in Reducing Social Stereotypes: Attitudinal Study and Computer Animation of Results for 4,000 Japanese Respondents. *American Society of Human Genetics*. Accepted.

Kohane, I.S.; Altman, R.B. 2005. Health-information altruists--a potentially critical resource. *New England Journal of Medicine*. 353(19):2074-7. doi:10.1056/NEJMsb051220

Lewis, K.; Kaufman, J.; and Christakis, N. 2008. The taste for privacy: An analysis of college student privacy settings in an online social network. *Journal of Computer-Mediated Communication, 14(1)*, 79-100.

McGowan, M.L.; Fishman, J.R.; Lambrix, M.A. 2010. Personal genomics and individual identities: motivations and moral imperatives of early users. *New Genet Soc*. Sep 1;29(3):261-290.

McGuire, A.L.; Diaz, C.M.; Wang, T.; Hilsenbeck, S.G. 2009 Social networkers' attitudes toward direct-to-consumer personal genome testing. *Am J Bioeth*. 9(6-7):3-10. doi: 10.1080/15265160902928209.

McKinney, M. 2013. HHS to develop data-sharing plan for outcomes research. *ModernHealthcare*.

Monegain, B. 2013. Data-sharing initiative reduces deaths. *Healthcare IT News*. March 19, 2013.

Phenx.org. 2014. https://phenx.org/

Portable Legal Consent. 2014. http://weconsent.us

Sanford Research. 2014. http://www.sanfordresearch.org/cords/

Swan, M. 2012. Crowdsourced Research Studies. *J Med Internet Res*. vol. 14, iss. 2, e46.

Swan, M. 2012a. Health 2050: The Realization of Personalized Medicine through
Crowdsourcing, the Quantified Self, and the Participatory Biocitizen. *J. Pers. Med. 2*(3), 93-118; doi:10.3390/jpm2030093

Swan, M. 2013. The Quantified Self: Fundamental Disruption in Big Data Science and Biological Discovery. *Big Data*. 1(2): 85-99.

TranSMART Foundation. 2014.
http://www.transmartfoundation.org/

Trotter, F. 2012. Who owns patient data? Blog entry. O'Reilly Web site.

Tung, J.Y.; Eriksson, N.; Kiefer, A.K.; Macpherson, J.M.; Naughton, B.T.; Chowdry, A.B.; Do, C.B.; Hinds, D.A.; Wojcicki, A.; and Mountain, J.L. 2011. Characteristics of an Online
Consumer Genetic Research Cohort. ASHG 2011 poster.

U.S. Census Bureau. 2012. Educational Attainment.
http://www.census.gov/hhes/socdemo/education/data/cps/2012/tables.html

U.S. Department of Health and Human Services. 2013. States prepare for seamless exchange of health records after disasters: Ten state HIE programs have established infrastructure for secure exchange of health information.

Utz, S.; Kramer, N. 2009. The privacy paradox on social network sites revisited: The role of individual characteristics and group norms. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace, 3*(2), article 1.

Viseu, A.; Clement, A.; and Aspinall, J. 2004. Situating privacy online: Complex perceptions
and everyday practices. *Information, Communication & Society*, 7(1), 92–114.

Weitzman, E.R.; Kaci, L.; Mandl, K.D. 2010. Sharing medical data for health research: the early personal health record experience. *Journal of Medical Internet Research* 12(2):e14.

Weitzman, E.R.; Kelemen, S.; Kaci, L.; Mandl K.D. 2012. Willingness to share personal health record data for care improvement and public health: a survey of experienced personal health record users. *BMC Med Inform Decis Mak*. May 22;12(1):39.