

An evaluation framework to assess educational genetic websites:

Are they meeting public needs?

Sara I. Crumb

A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2013

Committee:

Kelly Edwards

Helene Starks

Program Authorized to Offer Degree:

Public Health - Epidemiology

©Copyright 2013
Sara I. Crumb

University of Washington

Abstract

An evaluation framework to assess educational genetic websites: Are they meeting public needs?

Sara I. Crumb

Chair of supervisory committee:
Kelly Edwards, Associate Professor, Dept. of Bioethics and Humanities
Core Faculty, Institute for Public Health Genetics

The current focus of genetic research on complex diseases will require more research participants to be recruited. Informed consent can be difficult to achieve in these settings so the public should have the opportunity to become informed about genetic research prior to participating. To this end, the hopes—potential of genetics to improve health and individual benefits of participation—and concerns—security of information and discrimination—of various United States publics were determined by reviewing public opinion about genetics as reported in the literature. These concepts were used to develop an evaluation framework to assess how well public websites addressed these topics and other key genetic literacy concepts. The framework was tested in 7 educational websites. Screenshots of these seven websites can be found in the supplementary files. The tool showed the strengths of the sites as well as where there is room for improvement. Some websites are meeting some of the public’s needs but none are addressing every need. Public education and genetic literacy has room for growth and improvement if we are to accomplish our goal of an informed public to be future genetic research participants.

I. INTRODUCTION

Chronic diseases such as heart disease, mental illness, and type 2 diabetes are the current leading causes of death and disability in the United States and thus a top priority for public health.¹ Most of these common, chronic diseases occur because of a combination of multiple genetic and environmental risk factors. Oftentimes the effects of the individual genes in question are very small and can require thousands of data points to identify. To further develop our understanding of these complex gene-environment interactions, thousands of participants will need to take part in this research, sometimes participating in longitudinal cohort studies that gather environmental data over time as well as genetic data. Streamlining sample and data collection into biobanks and data registries will help researchers gather these vast amounts of data and chip away at what remains to be known about our genome. Biobanks allow researchers to access large numbers of samples without having to expend the resources to recruit participants themselves. This frees up more time and resources for the research itself, speeding up the pace of scientific discovery.

The use of biobanks in genomic research opens up many new challenges including the evolution of the consent process.² One particular challenge is that of informed consent in the face of the ever changing field of genomics research. Consent forms generally include information pertaining to the use and storage of participants' data and tissue samples both during and after the initial study. Enrolling participants and collecting tissue samples requires many resources, including collaborating with researchers who collect samples for other research purposes to ask participants for permission to use their tissue in other studies. The exponential growth of genomic research technology makes it hard to predict with any certainty what future studies will

entail and what ethical debates will arise so participants are often asked to give broad consent as it is impossible to predict the specific uses of their data at the time of consent.

Participants engaging in a typical consent process may not be truly informed when a study recruiter reads over the consent form and asks the potential participants if they have any questions. Studies show that many participants lack understanding of what they are consenting to, especially in the context of perceived benefits and risks of participation.^{3,4} If a potential participant is worried that her genetic information could be used against her and there isn't sufficient information on the consent form to assuage her concerns, she may be dissuaded from participating even if she thinks the study is a good idea. Or, if a participant believes he will receive treatment from the study, he may join the study under a false hope. The solution to this is not to address every issue on the consent form, as that would turn consent forms into novellas. Each individual will have his or her own hopes and concerns about participating and it would be nearly impossible to discuss each concern while keeping the consent form a manageable length. Instead, researchers and educators should ensure that potential participants have the opportunity to inform themselves about genetic research before they are even approached to be part of a study. I propose that the key to having truly informed participants is to start with an informed public.

Achieving this means developing informational and educational resources for the public. Education theory and attitude formation research suggest that it is not enough to provide someone with information; instead that information must be relatable, relevant, and delivered in a meaningful way.^{5,6} To make information about genetics and genetic research relevant to the lay public, we need to first understand what attitudes, hopes and concerns the public has about

genetics. Knowing what those hopes and concerns are, we can make sure to address them in meaningful ways.

For genetic information to be useful, a certain level of genetic literacy is necessary. Genetic literacy has been defined as having enough knowledge and understanding of genetic principles to make informed decisions both for one's self as well as for society.⁷ To achieve genetic literacy a person must have sufficient oral and written literacy to comprehend what they are reading as well as a basic grasp on numbers and mathematics, also known as numeracy, to comprehend genetic risk as well as inheritance patterns.⁷

Genetic literacy research conducted with members of different general publics has found a lack of understanding or incomplete understanding of genetics.^{8,9} At the heart of many of the misconceptions of genetics is the lack of numeracy. Individuals often believe that a genetic test holds more predictive power than it actually does and many don't understand the concept of the relative risk that a particular genetic variant might pose.⁸ Efforts to increase the public's genetic literacy have been called for by organizations and researchers alike, often citing that educating and empowering the public is one of the ten essential tasks of public health.^{7, 10}

The internet is a logical tool to use for dissemination of information to the public. The United States Census Bureau reported that in 2011, 71.7% of households had internet access, up from 54.7% in 2003.¹¹ Internet usage has become ubiquitous in the United States, so it would follow that it has the potential to reach a large number of people. Anyone with access to a computer and an internet connection can find an answer to almost any question. As a member of the first generation to grow up with computers and the internet, I can say that if I have a question, the first place I go for a quick answer is the internet. My experience is not unique: Rew

and colleagues discovered that their interviewees would likely go to the internet or their doctor with any questions about genetics and their health.¹²

With the power of the internet at nearly three-quarters of the population's fingertips, researchers and educators should use it to improve genetic literacy and foster a more informed public. It is with that purpose that I set out to develop an evaluation framework and tool to assess current educational websites based on the hopes, concerns, and gaps in knowledge of the public. I begin with a review of the literature on public opinions of genetics and genetic research. I used this literature review to develop criteria to evaluate educational and informational websites about genetics and genetic research. I then conducted an assessment of seven websites using this evaluation framework. This framework has the potential to be a useful tool to identify the strengths as well as the areas that need improvement in these websites and others like them.

II. PUBLIC OPINION LITERATURE REVIEW

The purpose of this literature review is to summarize what is known about the hopes and concerns that the United States public has with regard to genetic research. As such, this review includes studies with diverse purposes and diverse populations. These studies were selected based on the following criteria: (1) they must include data regarding U.S.-based public opinions of genetic research; (2) they must be in English; and (3) they must be available without payment. This approach serves to provide an overview of the U.S. public's hopes and concerns across a broad array of topics within genetic research.

Search Strategy

Literature searches were conducted between July and September of 2013 using the databases PubMed (PM) and Web of Science (WoS). The search terms used were "genetic*" and "public opinion" or "attitudes." Results were limited to English language and samples contained

within the United States (PM n=1763, WoS n=1209). While much of the public attitudes of genetic research literature is based in Europe, Asia, and Australia, the focus of this study is on the attitudes of US citizens largely because culture can influence attitudes and opinions. What is true for the Dutch population, for example, may not be true for the United States population. This initial search strategy yielded nearly 3000 papers, which were too many given the resources for this project. Thus, the search terms were limited to “genetic*” and “public opinion” with the same limits described above yielding 460 articles (PM n=403, WoS n=57). Articles were screened by title to remove those that were not studies and those not addressing public opinion of genetic research. This ruled out 365 articles and reduced the number of those potentially eligible to 95 (PM n=68, WoS n=27). Of these, ten were duplicates and two articles required payment to view. The remaining 83 papers were screened by abstract to determine if they should be included in the review here. Most of those ruled out did not include data about public opinions. In the final sample, 10 articles were found in PubMed and 6 were found in Web of Science for a total of 16 articles retrieved.¹³⁻²⁸ Through other readings, one additional article was identified and added²⁹ to the sample for a total of 17 articles discussed here (Table 1).

Table 1 Articles chosen for review

Year	Author	Unit and Sample Size	Population
2004	Achter et al. ¹³	Survey n=858	Members of the public in four regions of the US, and online, aged 18-73 years
2005	Bates et al. ¹⁴	9 Focus groups (n=91 individuals)	Members of the public in Georgia who were nominated by community advisory boards, aged 18-64 years
2005	Rose et al. ¹⁵	Survey n=961	Members of the US public contacted by random digit dialing, aged 18-97 years
2008	Kaufman & Geller et al. ¹⁶	16 Focus groups* (n=141 individuals)	Adult members of the public in 5 US cities: (Philadelphia, PA; Phoenix, AZ; Kansas City, MO; Jackson, MS; Portland, OR)
2008	Murphy et al. ¹⁷	16 Focus groups* (n=141 individuals)	Adult members of the public in 5 US cities: (Philadelphia, PA; Phoenix, AZ; Kansas City, MO; Jackson, MS; Portland, OR)
2008	Bussey-Jones et al. ¹⁸	Survey n=801 & Open ended subset n=194	Prior participants of a colorectal cancer study in North Carolina, mean age 64 years
2008	Kaufman & Murphy et al. ¹⁹	Survey n=4,659**	Members of the US public recruited by Knowledge Networks, aged 18-65+
2009	Kaufman et al. ²⁰	Survey n=4,659**	Members of the US public recruited by Knowledge Networks, aged 18-65+
2009	Kaufman & Murphy et al. ²¹	Survey n=931	US Veterans who had used VA services in the past, aged 18-75+
2010	Lemke et al. ²²	6 Focus groups (n=49 individuals)	NUgene biorepository participants, aged 26-67 years, and members of the public in Chicago, aged 19-70 years
2010	O'Daniel et al. ²³	10 Focus groups (n=100 individuals)	Members of the public in Durham, NC, aged 18-70+
2010	Trinidad et al. ²⁴	10 Focus groups (n=x individuals)	Adult Changes in Thinking study participants, surrogate decision makers, and the general public, aged 18-89
2011	Brothers et al. ²⁵	Survey n=677 & n=4,050	Vanderbilt faculty and staff & Nashville Community Health Survey, aged 18-65+
2011	Nwulia et al. ²⁶	Survey n=1,253	Participants in a bipolar genome study recruited from 11 institutions across the US, mean age 43 years
2011	Ruiz-Canela et al. ²⁷	Survey n=30	Adult participants in breast cancer and cystic fibrosis clinical trials
2012	Bollinger et al. ²⁸	10 Focus groups (n=89 individuals)	Members of the public in Washington, DC; Denver, CO; Philadelphia, PA; and social media users, aged
2013	Kerath et al. ²⁹	Survey & open response n=1,014	Adult members of the public recruited in six New York hospital waiting rooms

* Articles from the same study

** Articles from the same study

Results

The 17 papers represented 15 studies and reflected a variety of purposes, methodologies, and populations. Across this broad range of data, four topics were commonly addressed in the majority of the articles identified here: belief in the promise of genetic research (n=14), security of personal information (n=12), potential discrimination (n=11), and personal expectations of participation (n=10). Table 2 summarizes these themes, which are discussed further below.

Table 2 Literature review summary

Topic	Description	Citations
Promise		
Health	Belief that genetic research is important for improving health Belief that participating in research can directly benefit health	14, 15, 18, 22-25, 28
Science	Belief that genetic research is valuable or important for improving the understanding of disease	13, 14, 18-25, 28, 29
Security		
Trust	Some institutions and researchers are seen as more trustworthy than others	14, 20, 22, 25
Privacy	Concern about misuse of information by government and law enforcement	13, 14, 16, 20-22, 24-27, 29
Discrimination		
Legal	Concern about insurance premiums and coverage for self and family Concern about discrimination in employment	14-16, 18, 20-24, 26
Social	Concerns about stereotyping/stigma Concerns about racism Concerns about abuse of vulnerable populations	13-15, 18, 26
Expectations		
Individual Returned Results	Strong desire for receiving individual research results Strong desire for control over what results to receive	16, 17, 19, 21, 23, 27-29
Personal Benefit	Belief that the information could benefit the individual Belief that information would be empowering	17, 23, 28, 29
Family Implications	Concerns about family implications Belief that information could benefit family members	23

Over the decade that these studies were conducted, the same hopes and concerns were voiced by the publics represented, regardless of the methodology used to probe their opinions. Overall, the studies identified these broad points, which are discussed in detail below: Most people believe that genetic research is important for developing a better understanding of disease and thus improving health. Some believe that participating in research can have a direct positive impact on their health. The potential threat to personal security was a common concern. Personal security was discussed in two distinct ways. The first revolved around potential breaches of privacy that could lead to misuse of data. The second involved a sense of trust in the researchers or institutions conducting the study. Discrimination is generally talked about in the realm of insurance or employment but there are also concerns of stigma, genetics-fueled racism, and abuse of vulnerable populations. Finally there is a growing set of expectations for participating in

research. Potential participants want the option to receive individual research results because of the belief that the information could benefit them or their families. Many participants go so far as to say that returning results is just the right thing to do.

Promise of Genetic Research

The focus group discussions and surveys alike found that public support for genetic research is high. There exists a belief that it will improve overall health by treating and curing disease in the future and also by improving our understanding of diseases now. Questions of support are asked in many different ways. Achter et al. asked if tax payer dollars should be spent on genetics research and found that most agreed that they should.¹³ Others asked if a proposed study should be done and were met with majority support.^{19-21, 28} Brothers et al found that 99% of their survey respondents consider genetic research to be somewhat or very important to improving healthcare.²⁵ Even with this high level of support and belief in the promise of genetic research, the publics represented in these papers still expressed important concerns related to security, discrimination and implications for family members.

Security

The concerns relating to security were of two types: (1) general privacy concerns related to the misuse of data; and (2) trust of the institutions that may have access to their data or test results. Given the unique nature of each person's genome, concerns about keeping genetic information private are understandable and prevalent.^{13, 14, 16, 20-27, 29} Kerath et al. found that of those participants who would not readily join a biobank (~47%), nearly three quarters expressed concerns about privacy, indicating that this concern could be preventing people from participating in research.²⁹ However, genetic information is not necessarily of the utmost concern.^{20, 24, 27} Information about reproductive health and mental health was seen as potentially

more damaging if it were to be leaked than genetic information²⁴ and one study found that participants were more concerned about the privacy of their financial information (88%) than their medical information (79%).²⁰ This information should not be construed to mean that these publics don't want to keep their genetic information private. Instead, it indicates that although the concern is there, genetic information is not seen as exceptionally high risk.

Many of the publics studied in these papers view the government and corporations as a bigger potential threat to the security of their genetic and other information than anything else. There is a sense of distrust of for-profit companies doing genetic research^{14, 24} that is seated in the idea that a corporation's primary objective is to make money. Although the United States government is not in the business of turning a profit, members of the public are hesitant to trust it to reliably oversee research practices.^{22, 24} Some members of the public are concerned that the government^{13, 14, 24} or law enforcement agencies^{20, 21, 24} could use their genetic information against them.

The trustworthiness of different types of researchers was reported by Kaufman and colleagues in two studies.^{20, 21} They found that 80%²⁰ and 92%²¹ of study participants were supportive of sharing research data with other academic researchers. Support dropped by about 10% in each population when asked about sharing with government researchers and then dropped again when asked about sharing with pharmaceutical companies.^{20, 21} Other studies found similar results.^{24, 25} The acceptability of data sharing was explained well by a participant in Trinidad et al: "To me, the more information researchers have, the better, as long as you [can protect against discrimination]. I mean, that's what research is, and you're crippling it by not allowing them to share."²⁴ p.489

Discrimination

Fear of genetic discrimination is a common theme in public opinion studies, including studies conducted after the passage of the Genetic Information Nondiscrimination Act in 2008. Many articles cited the concern that insurance companies would use genetic information to charge higher premiums or deny coverage all together.^{14, 15, 18, 19, 22, 24, 26} Concerns about insurance can extend to the possible denial of insurance to a family member.¹⁵ As participants in Bates et al. suggested, these concerns are not unfounded because insurance companies use experience ratings to determine premiums, thus often charging people with preexisting conditions more. The fear is that insurance companies will view a genetic predisposition as a type of preexisting condition.¹⁴ Two studies found that 95%²¹ and 93%²⁰ of respondents felt it was important to make it illegal for insurance companies to have access to genetic research data or genetic test results indicating that this fear is widespread.

Discrimination in employment is another concern although on a smaller scale than that of insurance.^{14, 15, 19, 20, 22, 24, 26} Members of the public expressed worry that their employer might use a genetic predisposition toward a given illness as a reason to terminate or deny employment. Some saw it as a possible extension of mandatory drug testing which some companies already routinely perform.¹⁴ GINA makes this type of discrimination illegal, to the extent of including family medical history as a type of genetic information³⁰, but it cannot necessarily prevent discrimination so the fear persists.

Discrimination in obtaining medical insurance and discrimination in employment are certainly the most common concerns, but genetic discrimination on the basis of race or social status was also a concern identified in some of the studies. Some participants worried that the government could do research on vulnerable populations such as prison inmates.¹³ Others

thought that if a gene is found to be more common in African Americans, for example, that it could be used to promote racist ideas and stereotypes.^{15, 18} African Americans tended to have a stronger concern about the potential for racial discrimination based on genetics than their European American counterparts^{18, 26} which is unsurprising given the United States' history of racism paired with the Tuskegee syphilis study and sickle cell carrier testing.

Expectations

The studies also identified a set of expectations regarding what participating in genetic research would entail. A growing expectation is that of receiving individual research results. Some feel that it is the researchers' obligation to return research results that could be of clinical or personal importance.^{17, 28} Others feel that it would simply be a good incentive to participate.^{19, 21, 23} The desire to receive individual research results stems, in part, from the belief that these results could benefit participants or their families. If a result shows a predisposition toward a preventable disease, people felt they might be empowered to make lifestyle changes to reduce their risk.^{17, 28} If a result shows a predisposition toward a disease such as Alzheimer's that has few options for prevention or treatment, they reported they might use that information to make plans for the future.¹⁷ Many participants also would want the individual results even if there were no promise of personal or clinical utility.^{19, 21, 27, 29} While there are many reasons why a research participant may want to receive individual results, there was some consensus on how they want to receive them: Many participants want to have control over how many and what type of research results they would receive, if any at all.^{17, 19, 22}

In summary, the focus group discussions and survey results paint similar pictures. The public appears to have a generally positive opinion of genetic research and the potential it has to improve health. This support exists despite concerns of the possibility of discrimination, loss of

privacy, and the possible misuse of information. Lemke et al. specifically reported participants saying that despite their concerns, they still thought the research is valuable and necessary.²²

These studies also paint a picture of a future with more involved research participants: Ones who view a consent form as a contract and view getting their results back as compensation for participation. The survey research confirms that people want their results returned and the focus group studies report that many feel it is just the right thing to do. To encourage participation in the future, these concerns and hopes must be addressed in ways that are meaningful to the public.

III. DEVELOPMENT AND TESTING OF AN EVALUATION FRAMEWORK

The internet has become the go-to tool for finding information and thus can be used as an informal education medium to reach large numbers of people. There are many websites that talk about genetics and genetic research but whether any of them are meeting the public's needs by addressing their hopes and concerns has yet to be studied. Are those websites providing information that would be useful to an individual interested in research? Are they using effective tools to communicate that information? Are the websites addressing the hopes and concerns of the public? I will attempt to answer these questions in what follows.

Methods

Website Selection

When searching for educational websites about genetics, I tried to imagine what a person interested in genetics or participating in a genetic study might search the internet for. The search terms I chose were “genetics,” “genetic research,” and “genetic testing.” I searched for each of these terms using one of three search engines—Google.com, Bing.com, and Yahoo.com—on three different public computers. The purpose of using public computers was to avoid

contamination of search results through tracking programs such as Google’s search history personalization.³¹ The top three results for each search were recorded and yielded a total of 15 websites, accounting for duplicates (Table 3). To be included in the evaluation, the websites had to meet the following criteria. They needed to be: (1) geared toward a broad public audience; (2) have the purpose of providing information about genetics to that broad audience; and (3) be accessible to the public (i.e., not require special permission or passwords to access the content).

Table 3 Internet Search Results

Website	Hits	Description	Target Audience	Included
Wikipedia ³²	4	Crowd source encyclopedia	Public	Yes
23andMe* ³³	3	Direct to consumer genetic testing	Public	Yes
MedlinePlus ³⁴	1	Federal health and wellness website	Public	Yes
Learn.Genetics™ ³⁵	1	Educational website	Public & Teachers	Yes
GeneME* ³⁶	4	Nutritional supplement sales	Public	No
WiseGeek ³⁷	2	Question and answer forum	Public	No
Ancestry.com* ³⁸	1	Direct to consumer ancestry testing	Public	No
National Geographic* ³⁹	1	Direct to consumer ancestry testing	Public	No
Genetics.org ⁴⁰	3	Academic journal	Researchers	No
Seattle Genetics ⁴¹	2	Biotechnology company	Researchers	No
Cambridge Journals ⁴²	1	Academic journal	Researchers	No
AmbryGenetics* ⁴³	1	Research supplier	Researchers	No
DNA Center ⁴⁴	1	DNA testing (paternity, forensics, etc)	Researchers/Organizations	No
MHE† Research Foundation ⁴⁵	1	Disease organization	People affected by MHE	No
AccessExcellence ⁴⁶	1	National Health Museum	Teachers	No

*An asterisk denotes an advertisement.

†Multiple Hereditary Exostoses

The websites that were too specific, such as those aimed at a population affected by a specific disease or providing curriculum to school teachers, were excluded. They did not meet the criteria of being a website geared toward a broad public with a primary goal of being informational. The websites intended for researchers or organizations were also excluded because they are tailored to genetics experts, not the lay public. Among those with an intended audience of the general public, four were excluded. The WiseGeek site was excluded because it

had extremely limited information. It is not meant to be a resource about genetics but rather a question and answer forum for all topics. The two ancestry testing sites were excluded because they do not address genetics and health or science. The nutrigenomics website was intended to sell personalized nutritional supplements and made no claims to be a source of information about genetics. In comparison, 23andMe does present itself as a source of information, albeit limited, so it was included. From the internet searches, the following websites were included for evaluation because they met all the inclusion criteria: Wikipedia, 23andMe, Learn.Genetics, and NIH Medline Plus.

Upon discussion of these four websites with colleagues, we decided that the search results missed some sites that we were familiar with as public health genetics professionals. We decided to include three additional websites that are informational, meant for a broad public audience, and are from reliable organizations: The Genetic Alliance, the Wellcome Trust Sanger Institute and the website for the National Human Genome Research Institute (NHGRI). The Genetic Alliance is the leading genetic condition organization in the United States and developed the site Genes in Life⁴⁷ as a resource for the public. Similarly, the Wellcome Trust Sanger Institute is a prominent genomics center based in the United Kingdom and they developed Yourgenome.org⁴⁸ as a public resource. Although the focus of this paper is on the United States public, the nature of the World Wide Web makes borders less meaningful when it comes to sharing information. Finally, NHGRI is the genetics and genomics authority in the United States, we felt that any evaluation leaving out their website, Genome.gov,⁴⁹ would be incomplete. Table 4 lists the websites and their addresses.

Table 4 Websites Chosen for Evaluation

Website	Address	Source
Wikipedia	http://en.wikipedia.org/wiki/Introduction_to_genetics	Internet search
23andMe	https://www.23andme.com/	Internet search
Learn.Genetics™	http://learn.genetics.utah.edu/	Internet search
MedlinePlus	http://www.nlm.nih.gov/medlineplus/geneticstesting.html	Internet search
Genome.gov	http://www.genome.gov/	Expert opinion
Yourgenome.org	http://www.yourgenome.org/	Expert opinion
Genes in Life	http://www.genesinlife.org/	Expert opinion

Website Descriptions

Wikipedia is an open source, web-based encyclopedia run by the Wikimedia Foundation, Inc., a non-profit organization. The concept behind it is that everyone should have free access to information. The Wikimedia Foundation, Inc. set out to accomplish this by allowing the public to create and edit encyclopedia articles on Wikipedia. It is one of the most visited websites in the world.⁵⁰ The site reviewed here is intended to be an introduction to genetics³² that is accessible to all, as opposed to their main genetics article which is more technical.⁴⁰

23andMe is one of the most prominent direct to consumer genetic testing companies in the United States with over 400,000 genotyped customers as of 2013.⁵¹ They believe that it is important for people to have access to their genetic information and believe in providing the tools and education necessary to understand that information.⁵²

Learn.Genetics™ is an educational website geared toward students, teachers, and the public that was developed by the Genetic Science Learning Center at the University of Utah. The website is intended for non-expert audiences and covers topics in genetics and health. It is considered to be one of the most widely visited websites in the world with more than seven million unique visits in 2007.⁵³

MedlinePlus is a website run by the National Institutes of Health that provides information about diseases, conditions, and wellness. It is meant to be a reliable resource for the

public to find out about health issues, research, and clinical trials. Its genetics pages direct you to a resource called the Genetics Home Reference (GHR) which is intended to be a comprehensive yet easy to understand guide to genetics for the public.⁵⁴ Information for MedlinePlus and the GHR is taken from the National Library of Medicine.⁵⁵

Genome.gov is the official website for the NHGRI, which is one of 20 research institutes that make up the National Institutes of Health. Their mission is to understand “the structure and function of the human genome and its role in health and disease” while training investigators as well as disseminating information to the public.⁵⁶

Yourgenome.org is an informational website developed by the Wellcome Trust Sanger Institute which is Europe’s most prominent genome center and is based in the United Kingdom. The website includes information for the “intelligent non-expert” as well as more detailed information for people who are familiar with genetics.⁵⁷ Their purpose is to help inform the public about genetics and its implications.

Genes In Life was designed to be a public resource for people seeking information about genetics and how genetics plays a role in our lives. It was developed by the Genetic Alliance, which is a nonprofit health advocacy organization. Their goal is to help people make informed decisions about their health, specifically as their health relates to genetics.⁵⁸

Website Evaluation

The seven websites were evaluated using a four-point scale (Table 5) on the topics identified in the literature review as well as from a review of genetic literacy literature and elements of GINA (Table 6).

Table 5 Scoring Scheme

Score	Definition
0	No mention of topic
1	Mention with little to no detail
2	Detailed discussion
3	Detailed discussion + employment of educational tools (includes analogies, narratives, videos, diagrams, interactive elements, etc)

Table 6 Evaluation Criteria and Definitions

Topic	Definition	Source
Promise		
1. Health	Expected contribution of genetic research to health	Public Opinion
2. Science	Expected contribution of genetic research to science	Public Opinion
3. Logistics	Timeline and pace of genetic research	Genetic Literacy
Security		
4. Trust	What researchers may have access to data.	Public Opinion
5. Privacy	Protection of data from misuse.	Public Opinion
Discrimination		
6. Legal	Genetic Information Nondiscrimination Act of 2008	Law
7. Social	Stigma and stereotyping	Public Opinion
Expectations		
8. Individual Returned Results	What it would take to return results	Public Opinion
9. Personal Benefit	Clinical uses and limitations of research	Public Opinion
10. Family Implications	What personal results could mean for family members	Public Opinion
Genetic Literacy		
11. Risk	Interpreting genetic risk	Genetic Literacy
12. Heritability	How genes are passed from generation to generation	Genetic Literacy
13. The Basics	Genetics defined	Genetic Literacy

I assigned a score to each of the 13 possible elements (Table 6) by navigating through the websites. If there was no mention of a topic, the website would receive a score of zero. If there was a brief mention with little to no detail, a score of one was given. Detailed discussion of a topic would receive a score of two and finally detailed discussion plus the use of educational aids such as analogies, diagrams, narratives, or videos would garner a score of three.

In addition to scoring the content, three random samples of text were selected for determining the reading level of each website. It is recommended that information intended for the general public not be written above an 8th to 9th grade reading level to ensure its accessibility.⁵⁹ The online reading level tool at Readability-score.com was used to calculate the Flesch-Kincaid grade level reading score for each excerpt. For a description of the Flesch-Kincaid reading level calculation see.⁶⁰

Results

The websites received scores ranging from seven to 23 out of a total possible 39 points (Figure 1). While the overall scores say something about the comprehensiveness and quality of the websites, they do not provide much insight into the quality of information as they do not take into account that some sites scored very well in some areas and very poorly in others.

The following examples illustrate the different levels of detail associated with a score of 1 (little discussion) versus a more detailed discussion that would warrant a score 2 or 3 depending on whether or not additional tools were used.

Score of 1: “Find out if your children are at risk for inherited conditions, so you can plan for the health of your family.”³³”

Score of 2: “In some cases, genetic testing creates tension within a family because the results can reveal information about other family members in addition to the person who is tested.”³⁴”

Score of 3: “When we speak of the chance of inheritance of a gene or condition, we often use terms like “50%” or “1 in 2.” These numbers are a bit like tossing a coin. If you toss a coin, there is a 50% (or 1 in 2) chance that it will come up heads, and 50% that it will come up tails. If it does come up heads, and you toss it again, there is still a 50% chance of getting heads. The first toss doesn’t change the chance of getting heads a second time.⁴⁷”

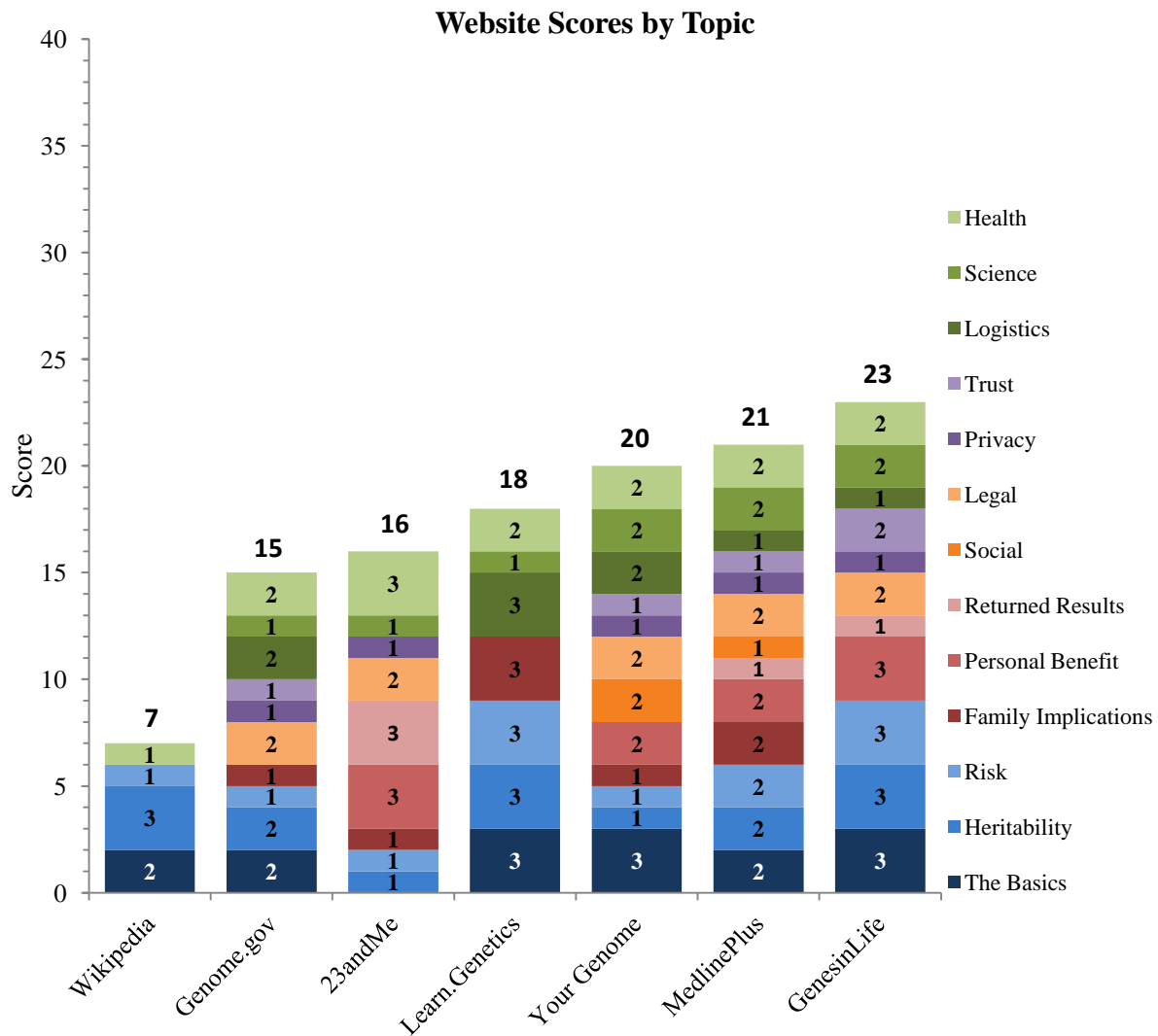


Figure 1 Website Scores by Topic

Evaluation by Website

Wikipedia

Wikipedia's page titled "Introduction to genetics" scored a total of 7 points. The reason for this score is that it focused only on the science and not the societal and personal implications of research. While most of the information (as of November 3, 2013) is very technical, there was one use of an analogy to help explain the process of chromosomal recombination as it relates to parents passing genes to their children:

"Genes are inherited as units, with two parents dividing out copies of their genes to their offspring. This process can be compared with mixing two hands of cards, shuffling them, and then dealing them out again. Humans have two copies of each of their genes, and make copies that are found in eggs or sperm—but they only include one copy of each type of gene³²."

The analogy is imperfect but it does point to how each offspring can get different genes from a given parent. Despite the analogy being worded in a way that is inconsistent with the recombination process, I still felt that this merited a score of 3. I would have expected Wikipedia's page to include information on the scientific process and the importance of genetics to basic science, given the content of the page but discussion of those two topics was missing. Also missing is a discussion of the ethical, legal, and social issues pertaining to genetics. Given the open source nature of Wikipedia's free encyclopedia, there is room for improvement through revisions and additions by Wikipedia contributors.

Genome.gov

Genome.gov scored a total of 15 points. The majority of these points were earned in the topics of promise and genetic literacy. As the NHGRI is one of the premier authorities on human genome research, its website is meant to provide information to the public. The homepage looks

inviting with photos and links to videos and news in the world of human genomics. However, once you click away from the homepage, you are met with walls of text with very few images.

There are thorough descriptions of genetics, genetic research, and anything else one may want to know about the science itself. The promise of genetics to improve health is discussed in detail and a realistic stance on the timeline of fulfilling that promise is taken:

“It is important to realize, however, that it often takes considerable time, effort, and funding to move discoveries from the scientific laboratory into the medical clinic. Most new drugs based on genome-based research are estimated to be at least 10 to 15 years away. According to biotechnology experts, it usually takes more than a decade for a company to conduct the kinds of clinical studies needed to receive approval from the Food and Drug Administration.⁶¹”

The information provided is accurate and detailed but again, the personal and societal implications of genetic research are missing from the discussion. The only mention of protection of privacy was in the context of the human genome project and the only mention of discrimination was that GINA exists to prevent discrimination in insurance and employment. What a person may expect out of participating in research, including the possibility of returning results, was not discussed anywhere that I could find in the hour and a half that I spent searching through the website.

Overall, the information provided was good, just incomplete, and at times hard to locate. As an example, the only mention I could find about what “genetic relative risk” means required that I click on a tab titled “Issues in Genetics,” then select “Regulation of Genetic Tests” from a drop down menu, then hover over “Regulation of Genetic Tests” which appears in a side bar to find a drop down menu with “A Brief Primer on Genetic Testing.” I had to read through the primer to find one sentence all the way at the bottom of the page that describes how most genetic tests will provide a relative risk rather than a definitive yes or no answer. Again, the information on this website is good information, it is just hard to digest and at times hard to find.

23andMe

23andMe has the goal of helping people make informed decisions about their health by using genetic information and their website scored 16 points. Given the for-profit nature of the company, it is unsurprising that much of their efforts are focused on what genetic testing can do for the consumer. The website is filled with personal stories and videos making the site (and product) very welcoming and likeable. The stories speak highly of the promise that genetics has to improve health but say very little about the actual risk calculations that the tests report. 23andMe also says very little about the science behind their tests. Much more information is available to those who purchase the genetic test but for those just browsing, there is very little information beyond general statements such as "Understand your genetic health risks. Change what you can, manage what you can't."³³

23andMe's website does have a detailed description of GINA to help assuage any concerns of being denied employment or insurance based on the results of having a genetic test done. They also assure that their customer's information will be kept private and well protected.

Overall, what little information 23andMe makes available to non-paying customers is delivered very well. As a consumer, I would want more information prior to purchasing their product but it makes sense, from a business standpoint, to hold back on detailed information until the purchase has been made.

Learn.Genetics™

Learn.Genetics™ is a well crafted educational site for those seeking information about genetics even though it scored 18—about half of the total possible points. The website is easy to navigate and it was very easy to find the information I was looking for. Multiple pages are cross-linked throughout the website so that there is more than one route to find the sought-after

information. There are many interactive animations on a variety of topics as well as some virtual labs. Through these activities, one can learn a lot about genetics and research.

Missing from this site was a discussion of the personal, societal, and legal implications of genetic research. It is an underlying theme of the website that the purpose of studying genetics is to learn about diseases and conditions to improve health. However, the only discussion of discrimination, privacy, and other ethical concerns is in relation to hot-button topics such as stem cell research and cloning. While these are important topics to cover, the implications of basic genetic research should not be omitted.

YourGenome.org

Yourgenome.org is a website that was developed by the United Kingdom's Wellcome Trust Sanger Institute to provide the public with information about genetics and genetic research. It scored a total of 20 points. The website has tabs directing you toward more information about a variety of topics from DNA to "Genomes, Health, and Society."⁴⁸ There are also links to basic information about genetics, as well as more detailed information readily available on the homepage. Upon clicking on any of these tabs or links, the resulting pages are broken down into small chunks of text with accompanying images and short videos. Many words have a hyperlink attached that connects to the website's glossary. Overall, it is an easy to navigate and easy to use website.

The idea of security is touched on briefly with comments alluding to other researchers having access to study data and the presentation of the question of whether or not genetic data can ever be kept truly private.

Discrimination was talked about in some depth. The protections that the UK has in place to prevent genetic discrimination were described and the potential for social stigma was

described too: "...grouping people according to their genes could have consequences too. People may end up being 'labelled' as not responding to a drug, or at risk of side-effects, which could have other effects in the life."⁴⁸ Yourgenome.org is one of only two sites (MedlinePlus being the other) to mention the potential for genetic discrimination to extend to a group.

Personal benefits of genetic research and family implications were discussed mainly within the context of preventing or treating disease and not in the context of returned results.

The animations on this website did a great job of demonstrating the basics of genetics but did not extend much beyond that. A very basic description of heritability was provided and although genetic risk was mentioned, no explanation was given of what "genetic risk" means.

Similar to the other websites, the promise of genetic research was discussed in some depth with regard to both health and science as a whole. Unlike some of the other websites, the promise was kept in check by a realistic attitude about the logistics of genetic research and research in general.

Yourgenome.org was the third highest scoring website but it only scored a 3 in one category. The addition of more teaching tools such as personal stories or diagrams could greatly improve the usability and accessibility of the information contained within its pages.

MedlinePlus/Genetics Home Reference

MedlinePlus itself has fairly limited information about genetics but on the pages "Genetic Testing"³⁴ and "Genetic Disorders"⁶² there is a featured direct link to the Genetics Home Reference (GHR)⁵⁴ which was developed by the National Library of Medicine and is meant to be a resource for the public to find information about genetics.

MedlinePlus—plus the GHR—was the only site to receive a score ≥ 1 for each of the 13 topics for a total score of 21. Many topics, especially those pertaining to the promise of research

and genetic literacy were discussed in detail. However, despite the claim that the GHR is meant to be a public resource, no tools to make the information more digestible were used. The GHR Handbook states that it is a source for information about genetics written in simple language and yet the language was fairly technical and was presented in walls of text. In addition, the graphics looked like they came out of a college textbook or a journal article.

Genes in Life

Genes In Life is a website developed by the Genetic Alliance to provide the public with information about genetics and genetic research. It earned the top score among the seven websites with a total of 23 points. Its homepage is nicely organized with descriptive tabs across the top addressing topics such as “Genetics 101” and “Genes & Your Health.” While navigating through the site I found that many words were hyperlinks that would take you to a glossary of terms. If you hovered over the word instead of clicking on it, a brief definition would pop up. This feature makes the site very readable as you don’t have to navigate away from what you are reading to look up definitions for unknown terms. While in some areas there is a lot of text, the text is broken up with videos and images.

This website was the only one to directly address the process of participating in research, and to make the distinction between research that involves being part of a clinical trial or registering with a biobank. They speak of the process that researchers would have to go through to access a participant’s data and briefly touch on how consent forms should outline privacy protections. On the topic of possible discrimination, this website is direct in saying that genetic discrimination could be a risk of participating but goes on to explain GINA and what it does and does not protect. Despite the mention of employment and insurance discrimination, there was no mention of the risk of stigma or stereotyping that could result from finding out genetic

information that may be common in a given ethnic or geographical group. Similarly, this website was the only one of the seven to address the idea of returning individual research results to participants. It also mentioned that some studies will have the option to return results and others will not, which earned it a score of one, but the topic was not entirely absent. The expectations of personal benefit from genetic research were addressed quite well, although the potential familial implications of receiving a genetic test result were absent.

Finally, much like the previous websites, Genes in Life scored highest in the areas of the promise of research and in developing the genetic literacy of the public. The educational animations that described genetics and inheritance were fun to watch and contained accurate information. The authors likened the risk of a child inheriting a trait or genetic disorder to rolling a set of dice each time a new child is conceived. This analogy is a good one to teach people that the odds are the same for each child at least when speaking about autosomal traits. When talking about the promise of genetic research to improve science as a whole and health, this website did a great job of showing examples, such as how the human genome project drove researchers to come up with better, faster sequencing tools and how with those better tools we may see improvements in health. The one part where these sections fell short was acknowledging that despite the great advances in technology, the process of getting a new drug or therapy from bench to bedside is still very slow.

Reading Levels

The Flesch-Kincaid grade level reading scores for the websites ranged from 7.9 to 14.0. A grade level score of over 12 indicates that the language used is at a college level. Due to the rather large difference in language used between the root page of MedlinePlus and the Genetics Home Reference (GHR) Handbook, the reading levels were calculated separately as reflected in

Table 8. Scientific terms often have many syllables (e.g. deoxyribonucleic acid), and syllables per word is part of the calculation of reading level.⁶⁰ Thus, by the nature of scientific terms, these scores may be inflated.

Table 7 Reading Grade Level of Websites

Website	Average Reading Level	Range
Wikipedia	8.8	7.4 – 9.9
Genome.gov	14	12.5 – 16.6
23andMe	8.6	7.0 – 11.7
Learn.Genetics	10.8	8.8 – 12.4
YourGenome	9.2	5.3 – 12.5
MedlinePlus	8.9	7.0 – 10.8
GHR Handbook	12.1	10.8 – 14.2
Genes in Life	7.9	7.6 – 8.4

DISCUSSION

The purpose of this evaluation was twofold: to (1) determine if these websites are addressing the issues that matter to the public, and (2) test the framework that I developed and determine if it could be a useful tool.

Are the websites meeting public needs?

The short answer to this question is that some are, some are not, and none are addressing all of the issues that I identified in the literature in a way that is meaningful and accessible to the public. Among these seven websites, there is a lot of accurate information about genetics, genetic research, and what genetics could do for the individual and society. There is also a general lack of information about the ethical, legal, and social issues pertaining to genetic research, especially in the realm of individual returned results. The individual strengths and weaknesses of the

websites may be due, in part, to the slightly different foci of the websites evaluated here. It may be the case that the NHGRI doesn't want to talk about returning individual research results because it is currently a topic that is up for debate among researchers and academics.⁶³ It may be that MedlinePlus doesn't see a need to include educational tools because it is an online offshoot of a library. I would argue that as federally-funded and -run websites, they have a duty to meet the needs of the public and part of meeting those needs is addressing the topics that are important to them.

The Genetic Alliance's page, Genes in Life, comes the closest to meeting public needs and the Wellcome Trust Sanger Institute's Yourgenome.org does a fairly good job too. These two websites did not, however, come up in the nine internet searches that I conducted. So while they provide accurate information in a format that better meets the needs of the public, they are not as visible as the other websites evaluated here. The best information does little good if it cannot be found readily.

The average reading levels of the seven websites are generally not excessively higher than the average reading level of the United States population which sits at the 8th to 9th grade level.⁵⁹ MedlinePlus's Genetics Home Reference and the NHGRI's genome.gov sites are, however, written at a college reading level which may be too high to reach the majority of the population.

Testing the Framework

This framework has the potential to be a useful guide for completing a directed content analysis of websites that are geared toward educating the public about genetics. I think that the focus on promise, security, discrimination, expectations, and genetic literacy worked well to illustrate the emphasis that each website has. Most notably, the Wikipedia page is meant to be an

encyclopedia and it scored fairly well in the realm of facts. An encyclopedia generally doesn't offer conjecture about a topic so the lack of information about security, discrimination, and expectations from participating in research are not necessarily a bad thing for Wikipedia. In contrast, Genes In Life is meant to be a resource for people interested in genetics and genetic research so it is not surprising that it scored the highest of the seven websites. 23andMe is profit driven so it makes sense that they are not providing that much information up front. That being said, the topics I identified as important to the public do not include any proprietary information, and 23andMe has partnered with other organizations to make some of the educational videos that other sites in this evaluation have used.⁴⁷

One difficulty that I encountered when using the scorecard was differentiating between the promise of genetics to improve health in general and the expected benefit of research to improve a participant's health. Oftentimes a sentence that I would classify under the former topic could be read as the latter if viewed through the lens of a person who wants to participate in research. Having more than one reader and evaluator would help clarify the difference between the two.

Limitations

The primary limitation of this analysis is that I was the only evaluator, thus the reproducibility of these results is unknown. In addition, as a public health genetics student, I am knowledgeable in genetics and its ethical, legal and social implications and it is impossible for me to truly put myself in the shoes of a lay person. My interest in genetic literacy also limits my ability to think like a lay person. As such, there is the possibility that my internet search terms are not what a lay person would search for and it is possible that the themes I identified in the public opinion literature were influenced by my background. Finally, this project is primarily a

proof of concept rather than a true evaluation. The evaluation framework likely has room for improvement and a more thorough evaluation with multiple readers should be performed to truly test utility of the scoring scheme. Perhaps the ultimate test would be to hand the evaluation framework over to a group of lay persons and have them evaluate the websites.

Implications

This project sheds some light on the state of educational websites about genetics and genetic research. By identifying the areas that could use some improvement, the organizations that maintain and develop websites, such as those evaluated here, can work to enhance their content and bring it to a level that is truly accessible and meaningful.

There is also the question of how easy it is to find these websites. Two of the most comprehensive sites, Genes in Life and Yourgenome.org, did not appear in the top search results. Also, many of the top results were advertisements for direct to consumer ancestry and nutrigenomics testing. Further research should be conducted to explore how to improve search result listings in the top internet search engines. If top spots are assigned based on the number of hits or based on payment, such as the case of the advertisements, research into the ethics of these practices should be conducted. The internet has the capability to be a great resource, full of accurate and meaningful information, but it also has the potential to dilute that good information with unsubstantiated information.

To foster an informed public, from which many members may become research participants, we must ensure that accurate and meaningful information is made available. Websites such as those evaluated here can be effective resources for the public. In order to ensure maximum usability, we must first address the issues of content, visibility, and delivery

discussed here. The evaluation framework tested here could be used more widely to ensure the highest quality and most informative sources for the public and future research participants.

REFERENCES

1. CDC. Chronic Disease Prevention and Health Promotion. November 19, 2013. Available at: <http://www.cdc.gov/chronicdisease/>. Accessed November 20, 2013, 2013.
2. Knoppers BM, Zawati MH, Kirby ES. Sampling populations of humans across the world: ELSI issues. *Annu Rev Genomics Hum Genet.* 2012;13:395-413.
3. Falagas ME, Korbila IP, Giannopoulou KP, Kondilis BK, Peppas G. Informed consent: how much and what do patients understand? *Am J Surg.* Sep 2009;198(3):420-435.
4. Rose D, Russo J, Wykes T. Taking part in a pharmacogenetic clinical trial: assessment of trial participants understanding of information disclosed during the informed consent process. *BMC Med Ethics.* 2013;14:34.
5. Connor M, Siegrist M. Factors Influencing People's Acceptance of Gene Technology: The Role of Knowledge, Health Expectations, Naturalness, and Social Trust. *Science Communication.* 2010;32(4):514-538.
6. Collins J. Education techniques for lifelong learning: principles of adult learning. *Radiographics.* 2004 Sep-Oct 2004;24(5):1483-1489.
7. Syurina EV, Brankovic I, Probst-Hensch N, Brand A. Genome-based health literacy: a new challenge for public health genomics. *Public Health Genomics.* 2011;14(4-5):201-210.
8. Klitzman RL. Misunderstandings concerning genetics among patients confronting genetic disease. *J Genet Couns.* Oct 2010;19(5):430-446.
9. Condit CM. Public attitudes and beliefs about genetics. *Annu Rev Genomics Hum Genet.* 2010;11:339-359.
10. McBride CM, Bowen D, Brody LC, et al. Future health applications of genomics: priorities for communication, behavioral, and social sciences research. *Am J Prev Med.* May 2010;38(5):556-565.
11. File T. Computer and Internet Use in the United States. In: Bureau USC, ed; 2013.
12. Rew L, Mackert M, Bonevac D. Cool, but is it credible? Adolescents' and parents' approaches to genetic testing. *West J Nurs Res.* Aug 2010;32(5):610-627.
13. Achter P, Parrott R, Silk K. African Americans' opinions about human-genetics research. *Politics Life Sci.* Mar 2004;23(1):60-66.
14. Bates B, Lynch J, Bevan J, Condit C. Warranted concerns, warranted outlooks: a focus group study of public understandings of genetic research. *Social Science & Medicine.* Jan 2005 2005;60(2):331-344.
15. Rose A, Peters N, Shea J, Armstrong K. The association between knowledge and attitudes about genetic testing for cancer risk in the United States. *Journal of Health Communication.* Jun 2005 2005;10(4):309-321.

16. Kaufman D, Geller G, Leroy L, Murphy J, Scott J, Hudson K. Ethical implications of including children in a large biobank for genetic-epidemiologic research: A qualitative study of public opinion. *American Journal of Medical Genetics Part C-Seminars in Medical Genetics*. Feb 15 2008 2008;148C(1):31-39.
17. Murphy J, Scott J, Kaufman D, Geller G, LeRoy L, Hudson K. Public Expectations for Return of Results from Large-Cohort Genetic Research. *American Journal of Bioethics*. 2008 2008;8(11):36-43.
18. Bussey-Jones J, Henderson G, Garrett J, Moloney M, Blumenthal C, Corbie-Smith G. Asking the Right Questions: Views on Genetic Variation Research Among Black and White Research Participants. *Journal of General Internal Medicine*. Mar 2009 2009;24(3):299-304.
19. Kaufman D, Murphy J, Scott J, Hudson K. Subjects matter: a survey of public opinions about a large genetic cohort study. *Genetics in Medicine*. Nov 2008 2008;10(11):331-339.
20. Kaufman D, Murphy-Bollinger J, Scott J, Hudson K. Public Opinion about the Importance of Privacy in Biobank Research. *American Journal of Human Genetics*. Nov 13 2009 2009;85(5):643-654.
21. Kaufman D, Murphy J, Erby L, Hudson K, Scott J. Veterans' attitudes regarding a database for genomic research. *Genetics in Medicine*. MAY 2009 2009;11(5):329-337.
22. Lemke A, Wolf W, Hebert-Beirne J, Smith M. Public and Biobank Participant Attitudes toward Genetic Research Participation and Data Sharing. *Public Health Genomics*. 2010 2010;13(6):368-377.
23. O'Daniel J, Haga S. Public Perspectives on Returning Genetics and Genomics Research Results. *Public Health Genomics*. 2011 2011;14(6):346-355.
24. Trinidad S, Fullerton S, Bares J, Jarvik G, Larson E, Burke W. Genomic research and wide data sharing: Views of prospective participants. *Genetics in Medicine*. Aug 2010;12(8):486-495.
25. Brothers KB, Morrison DR, Clayton EW. Two large-scale surveys on community attitudes toward an opt-out biobank. *Am J Med Genet A*. Dec 2011;155A(12):2982-2990.
26. Nwulia E, Hipolito M, Aamir S, Lawson W, Nurnberger J, Consortium B. Ethnic Disparities in the Perception of Ethical Risks From Psychiatric Genetic Studies. *American Journal of Medical Genetics Part B-Neuropsychiatric Genetics*. Jul 2011;156B(5):569-580.
27. Ruiz-Canela M, Valle-Mansilla J, Sulmasy D. What Research Participants Want to Know About Genetic Research Results: The Impact of "Genetic Exceptionalism". *Journal of Empirical Research on Human Research Ethics*. Sep 2011 2011;6(3):39-46.
28. Bollinger J, Scott J, Dvoskin R, Kaufman D. Public preferences regarding the return of individual genetic research results: findings from a qualitative focus group study. *Genetics in Medicine*. Apr 2012 2012;14(4):451-457.
29. Kerath SM, Klein G, Kern M, et al. Beliefs and attitudes towards participating in genetic research - a population based cross-sectional study. *BMC Public Health*. 2013;13:114.
30. Genetic Information Nondiscrimination Act of 2008. 110th Congress Second Session ed. United States: U.S. Government Printing Office; 2008:881-922.
31. Basics: Search history personalization. *Google*. Available at: <https://support.google.com/accounts/answer/54041?hl=en>. Accessed October 31, 2013.
32. Introduction to genetics. *Wikipedia, The free encyclopedia*. Available at: http://en.wikipedia.org/wiki/Introduction_to_genetics. Accessed November 3, 2013.

33. 23andMe. *23andMe, Inc.* Available at: <https://www.23andme.com/>. Accessed November 3, 2013.
34. Institute NHGR. Genetic Testing. *US National Library of Medicine*. Available at: <http://www.nlm.nih.gov/medlineplus/genetictesting.html>. Accessed November 11, 2013.
35. Learn.Genetics. *The University of Utah Genetic Science Learning Center*. Available at: <http://learn.genetics.utah.edu/>. Accessed November 5, 2013.
36. geneME DNA customized nutrients. Available at: <http://genemednareport.com>. Accessed October 31, 2013.
37. What is Genetic Research? *Conjecture Corporation*. Available at: <http://www.wisegEEK.com/what-is-genetic-research.htm>. Accessed October 31, 2013.
38. ancestryDNA. *Ancestry.com*. Available at: <http://dna.ancestry.com/>. Accessed October 31, 2013.
39. The Genographic Project: Buy the kit. *National Geographic Society*. Available at: <http://shop.nationalgeographic.com/ngs/browse/productDetail.jsp?productId=2001246>. Accessed October 31, 2013.
40. Genetics. *Wikipedia, the free encyclopedia*. Available at: <http://en.wikipedia.org/wiki/Genetics>. Accessed October 31, 2013.
41. Seattle Genetics. *Seattle Genetics, Inc.* Available at: <http://www.seattlegenetics.com/>. Accessed October 31, 2013.
42. Genetics Research. *Cambridge Journals*. Available at: <http://journals.cambridge.org/action/displayJournal?jid=GRH>. Accessed October 31, 2013.
43. Exome Sequencing Services. *Ambry Genetics Corp.* Available at: <http://www.ambrygen.com/exome-sequencing-services>. Accessed October 31, 2013.
44. DNA Diagnostics Center. *DNA Diagnostics Center*. Available at: <http://www.dnacenter.com>. Accessed October 31, 2013.
45. The MHE Research Foundation. Available at: <http://www.mheresearchfoundation.org>. Accessed October 31, 2013.
46. Schmeck H. The Future of Genetic Research. *Access Excellence @ the National Health Museum*. Available at: http://www.accessexcellence.org/RC/AB/IE/Future_Of_Genetic_Research.php. Accessed October 31, 2013.
47. Genes In Life. *Genes in Life*. Available at: <http://www.genesinlife.org/>. Accessed November 13, 2013.
48. YourGenome.org. *Wellcome Trust Sanger Institute*. Available at: <http://www.yourgenome.org/>. Accessed November 13, 2013.
49. Genome.gov. *National Human Genome Research Institute*. Available at: <http://www.genome.gov/>. Accessed November 5, 2013.
50. Frequently Asked Questions. *Wikimedia Foundation*. Available at: <http://wikimediafoundation.org/wiki/FAQ/en>. Accessed November 3, 2013.
51. Fact Sheet. *23andMe, Inc.* Available at: <http://mediacenter.23andme.com/fact-sheet/>. Accessed November 3, 2013.
52. About Us: Core Values. *23andMe, Inc.* Available at: <https://www.23andme.com/about/values/>. Accessed November 3, 2013.

53. About Us. *The University of Utah Genetic Science Learning Center*. Available at: <http://learn.genetics.utah.edu/gslc/>. Accessed November 5, 2013.
54. Genetics Home Reference Handbook. *US National Library of Medicine*. Available at: <http://ghr.nlm.nih.gov/>. Accessed November 11, 2013.
55. About MedlinePlus. *US National Library of Medicine*. Available at: <http://www.nlm.nih.gov/medlineplus/aboutmedlineplus.html>. Accessed November 11, 2013.
56. Mission Statement. *National Human Genome Research Institute*. Available at: <http://www.genome.gov/10001022>. Accessed November 5, 2013.
57. About us. *Wellcome Trust Sanger Institute*. Available at: <http://www.yourgenome.org/help/>. Accessed November 13, 2013.
58. About Us. *Genes In Life*. Available at: <http://www.genesinlife.org/about-us>. Accessed November 13, 2013.
59. Doak C, Doak L, Root J. *Teaching Patients with Low Literacy Skills*. Second ed: Lippincott Williams & Wilkins; 1995.
60. Kincaid J, Fishburne R, Rogers R, Chissom B. Derivation of New Readability Formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy Enlisted Personnel. In: Command NTT, ed. Millington, Tennessee: United States Navy; 1975.
61. A Brief Guide to Genomics. *National Human Genome Research Institute*. Available at: <http://www.genome.gov/18016863>. Accessed November 5, 2013.
62. Genetic Disorders. *US National Library of Medicine*. Available at: <http://www.nlm.nih.gov/medlineplus/geneticdisorders.html>. Accessed November 11, 2013.
63. Wolf SM. Return of individual research results and incidental findings: facing the challenges of translational science. *Annu Rev Genomics Hum Genet*. 2013;14:557-577.