

**Public Attitudes Toward Genetics & Genomics Research**

**Literature and Polling Review Report**

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For the American Society of Human Genetics**

## TABLE OF CONTENTS

EXECUTIVE SUMMARY.....	3
SUMMARY OF FINDINGS .....	4
I. Genetic and Genomic Research: General Public Awareness and Knowledge.....	4
II. Genetic Testing: Clinical & Direct-to-Consumer.....	4
III. Gene Editing .....	8
IV. Concerns: Ethical, Privacy, Discrimination, Stigma, Psychological Harm.....	10
V. Racial & Ethnic Minority Populations.....	11
VII. Gene Therapy: Pharmacogenomics & Personalized Medicine .....	12
VII. Epigenetics: Genetic Determinism, Genes-Environment Influences .....	13
VIII. Federal Funding of Genetics Research.....	14
CITATIONS.....	15
ADDITIONAL REFERENCES .....	17

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*The material was reviewed by chairs of the ASHG Public Education and Awareness Committee and the Government and Public Advocacy Committee and approved by the ASHG Executive Committee for publication. All efforts were made to gather relevant studies, limited to those in the English language, and summarize content with attention to limitations and needs for further study. We refer readers to the full text of articles for full findings and context. Errors and omissions are the responsibility of ASHG staff, and any corrections will be updated in future versions.*

## EXECUTIVE SUMMARY

In August 2019, the American Society of Human Genetics (ASHG) undertook a review of the academic literature and national polls/surveys on the topic of public attitudes toward genetic research. The articles and poll reports included in the review were published primarily between 2009 and 2019, with a few sources dating back to 2004. In all, the project reviewed 97 academic articles and 28 polls. The respondents to all polls were members of the U.S. public. Most articles covered in the literature review also addressed American public attitudes; however, a small number of articles are included describing particularly relevant studies of the general population attitudes in other western nations.

- **U.S. public awareness of the field of genetics was high.** The public was consistently found to hold positive attitudes toward genetics research and optimistic views of its potential to improve human health through disease prevention, risk detection and related behavior modifications.
- **These positive attitudes existed despite the fact that knowledge among the public about genetics was generally low.** Studies have found no clear pattern in assessing links between level of genetic knowledge and attitude toward genetics.
- **Positive attitudes, however, depended on the area of genetics and how genetic technologies will be applied.** Genetic testing and other technologies that lead to detection, prevention, and/or treatment of disease are viewed very favorably, particularly those where testing can be followed by clinical action. In contrast, the public expresses negative attitudes toward the use of technologies for sex selection, cosmetic features, or to “screen” for characteristics such as low IQ or homosexuality.
- **On direct-to-consumer genetic testing, a few studies have observed that the most extreme scenarios predicted have not materialized**—neither the great improvements in positive health behaviors nor the severe emotional distress, misunderstanding of results, or undue burden on the health system.
- **The most common system-level concerns about genetic testing and use of genetics in medicine focused on privacy, potential discrimination by insurers/employers, and cost/insurance coverage.** As noted in one study, “For many people, concerns about privacy may not be an absolute deal-breaker that precludes participation in research but, rather, may be one of a list of several pros and cons that are weighed in deciding whether or not to participate.”
- **The American public supported gene editing in certain instances—for instance, to improve someone’s health—but shows low support for editing to boost IQ, appearance, or abilities, or for editing genes before birth, unless it might reduce the risk of serious disease.** Most Americans favored gene therapy for clinical use in patients with serious disease. Most did not support editing in human embryos or germline cells, but the level of opposition varied depending on its goals.
- **While there were limited data on concepts such as pharmacogenetics and epigenetics,** some reports suggested the public understood the ideas, even when those terms were new to them, and there was interest in understanding how they would influence health and disease.

## SUMMARY OF FINDINGS

The following report summarizes the findings from the literature and polling data review undertaken by ASHG. Findings are structured around the main topics that emerged in the review. A list of references follows the report.

### I. Genetic and Genomic Research: General Public Awareness and Knowledge

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#### **Literature Review**

Public awareness of genetics was high, even though clear understanding of the field was not.

In the publications we reviewed, all were consistent in finding that U.S. public opinion was positive about genetic research where there were clear medical benefits. Despite generally low knowledge levels, the public held optimistic views toward this field of research, particularly its potential to improve human health through disease prevention, risk detection, and related health behavior modifications.

In one 2019 study, roughly 2,000 Jackson and Framingham study participants described their views of genetic research as “hopeful” (60-70%), “optimistic” (44-64%), “enthusiastic” (35-43%), or “excited” (28-30%). Fewer used negative words such as “cautious” (35-43%), “concerned” (25-55%), “worried” (6-13%) and “pessimistic” (2-5%). (Saylor et al., 2019)

Greater knowledge of genetics did not always translate to more positive attitudes. Some studies showed limited associations of knowledge level with attitudes, while others suggested that individuals with greater knowledge had greater concerns about genetic technologies and less positive attitudes about their widespread use. (Carver, 2017) According to Etchegary (2014), “a well-informed public may in fact be more discriminating and display a critical attitude toward specific issues within science, particularly those of a socially or morally sensitive nature.” A number of research teams concluded that personal values and experiences played a significant role in shaping beliefs and attitudes about genetics.

Most studies found genetic knowledge among urban populations to be stronger than in rural populations. Knowledge levels also varied among racial/ethnic groups and across educational attainment and income levels.

#### **Polling Data Review**

The polls reviewed focused on specific aspects of genetic research, rather than genetics in general.

### II. Genetic Testing: Clinical & Direct-to-Consumer

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#### **Literature Review**

As with attitudes toward genetic research broadly, public attitudes toward genetic testing were highly favorable for health purposes. However, the public did have concerns (summarized in Section IV).

Many studies included in this review identified a relationship between knowledge of and attitudes about genetic testing and willingness to participate in it. Often, individuals with less knowledge were more supportive of genetic testing than were those with greater knowledge, and those with lower education levels were more optimistic about the potential of genetic testing to address human disease.

Barriers to participating in genetic testing included lack of awareness of the tests, confidentiality concerns and difficulty of accessing genetic testing.

Genetic testing and other technologies that lead to detection, prevention and/or treatment of disease were viewed very favorably, particularly when they can lead to clinical action. In contrast, the public held negative views on the use of technologies for cosmetic features, sex selection, or preventing or diagnosing low IQ or homosexuality. (Etchegary, 2014<sup>1</sup>)

A 2019 Dutch study found that the acceptability of genetic testing, consideration of it and intent to be tested were stronger among those with lower knowledge of genetic principles. Younger age groups were more likely to find genetic testing acceptable and consider being tested. (Stewart et al., 2018<sup>2</sup>) Similar patterns have been observed in the U.S. public.

In a review of 21 studies with 3,934 parents, parents held largely positive views about genetic testing for their children. Childhood genetic testing was seen by most parents as beneficial. (Lim et al., 2017<sup>3</sup>)

In a 2015 national survey, 60% of Americans expressed interest in genome sequencing (GS), and parents expressed similar interest in GS for themselves (61.8%) and their children (57.8%). The survey found a strong link between conservative ideology and lower interest in GS. No significant link was noted between race and interest in WGS. (Dodson et al., 2015)

In a 2018 analysis of the National Cancer Institute's annual Health Information National Trends Survey (HINTS), 2011-2014, rural residents were less likely to be aware of genetic testing. (Salloum et al., 2018) In contrast, a small 2019 qualitative study among rural residents found that most were aware of and had a positive view of genetic testing. Yet over half were concerned about insurers accessing the results and said the lack of access to testing and/or genetic counseling nearby was a barrier. (Fogleman et al., 2019<sup>4</sup>)

In one survey, 65% responded that clinicians should be involved in explaining genetic test results. (Almeling & Gadarian, 2014)

### Direct-to-Consumer Testing

The number of people globally who have taken a DTC genetic test tops 25 million, according to the two largest

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<sup>1</sup> Limitations/future research: The breadth of literature on public attitudes about genetic testing and genomic technologies, with its varied measures, makes comparisons across studies difficult. Most research designs are cross-sectional and not guided by a formal attitude theory, hindering observation of attitude changes over time. Still in its infancy, research on behavioral effects of providing genetic risk information for complex, common disease should be a priority. Research is needed to assess if and how understanding of genomic risk can favorably influence health outcomes—ideally using systematic steps to overcome methodological weaknesses of first-generation studies (e.g., small sample sizes, retrospective designs and restricted populations). Health communication research is needed to learn what information fosters accurate understanding and interpretation of genomic information, across varying health literacy levels. Most studies of beliefs and attitudes about genetics, first, have not engaged with scientific theories of attitude/belief formation; second, have not focused on changing trends in attitudes and beliefs; and third, have not fully explored aspects of attitudes that may have implications for genetic health services or policies. Public opinion and engagement research are critical for informed debate and input on integrating genomic technologies into healthcare and realizing personalized medicine's promise.

<sup>2</sup> Limitations: Many respondents had not previously heard of DTC genetic testing. An introduction to the topic was included at the beginning of the survey. Many respondents had to base their answers on this brief description, and so their responses were likely intuitive. Further, given the phenomenon of intention-behavior gap, the factors this study associated with consideration and intent may not reflect factors of actual uptake.

<sup>3</sup> Limitations/further research: Parents' education level, genetic status, sex and sociodemographic status were associated with reported attitudes; this yielded some conflicting findings, indicating the need for further research.

<sup>4</sup> Limitations: The small sample size did not allow for exploring differences in knowledge, attitudes and perceived barriers by demographic characteristics. The sample may not be representative of rural populations elsewhere (e.g., the majority of participants

providers: 23andMe (10 million customers) and Ancestry.com (15 million). Other, emerging companies (e.g., Habit, Promethease) urge consumers to share test results so that these companies can do other analyses of the data. (A 23andMe-GSK partnership is analyzing data of customers who opt-in.)

While promotion and discussion of direct-to-consumer (DTC) genetic testing may seem ubiquitous, a number of studies found awareness of it to be hovering below 50%. According to a 2018 analysis of HINTS, 2007-2014, the percentage of Americans who were aware of direct-to-consumer (DTC) genetic testing was 30.6% in 2007, peaked at 48.9% in 2012 and declined to 38.4% in 2014. Awareness was greater among those who use the Internet and have higher incomes, more education, and health insurance. Only in 2011 and 2014 did awareness differ significantly by race or ethnicity. From 2007 to 2014, the awareness gap decreased between older and younger age groups. However, the gap is growing between Internet users and non-users: Internet users showed much higher awareness of DTC genetic testing since 2012 and by 2014 were twice as likely to know about it. Rural residents were much less likely to be aware of DTC testing than urban residents. (Apathy et al., 2018<sup>5</sup>)

Regarding fears of negative psychological effects from DTC testing, an analysis of studies using data from the Impact of Personal Genomics (PGen) study found that anxiety, distress, and worry were low or absent after receiving results, and even that effect faded in time. For example, the analysis cited Bloss et al., 2013, as finding no significant test-related distress (TRD) immediately after receiving results and, even so, a significant decrease in TRD between three months and one year afterward (score of >8 and >23 points on avoidance and intrusion subscales indicate “some impact” and “clinically relevant distress,” respectively; 1-year FU =  $1.2 \pm 3.4$ , 96.8% scored <8, and 99.7% scored <23). (Stewart et al., 2018<sup>6</sup>) On the other hand, 38% of DTC testing users said they had not considered the possibility of unwanted information before purchasing these services. (Roberts et al., 2017)

Academic reviews found generally high levels of interest in testing in a clinical setting. Factors strongly associated with awareness, knowledge and interest in clinical genetic testing included being more educated, female, white, married, and having a family history of cancer. (Peterson et al., 2018<sup>7</sup>)

In a 2017 study of 941 customers of two personal genomic testing companies, participants supported including genetic information in medical records (28%) and restricting testing to clinical settings (14%). Those who perceived elevated risk from their results showed lower support for expanded availability and incorporation of PGT into health care. Those upset by their results were less likely to support access to DTC products without a medical professional. (Gollust et al., 2017<sup>8</sup>)

A 2015 survey of 1,093 customers of 23andme and Pathway Genomics found that most could correctly interpret hypothetical genetic test results. Genetic knowledge and numeracy were strongly associated with comprehension, suggesting that genetic knowledge alone may be insufficient without numeracy. As of 2015, DTC genetic testing customers tended to be well educated, with strong numeracy skills and genetic

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had at least some college education). Those who consent to participate in a genetic study are likely to be knowledgeable and hold more favorable views toward genetic testing. This study did not differentiate the implications of testing for single known gene mutations vs. multiplex gene panels.

<sup>5</sup> Limitations: Assessing DTC testing awareness via a single HINTS question is a coarse indicator. HINTS cannot track people over time and may suffer from nonresponse and selection biases. Selection bias may limit generalizability.

<sup>6</sup> Limitations may exist in the primary studies: Reported estimates largely are not compared to control; social desirability and self-reporting may have led to reporting bias and overestimated effects; percentages of positive lifestyle changes and sharing with a healthcare provider may have been underestimated; five publications’ participants were considered “non-actual” consumers of testing; some meta-analyses drew on just a few studies; and meta-analyses showed great heterogeneity, and no subgroup analyses were possible on follow-up duration.

<sup>7</sup> Limitations: Studies reviewed had little focus on minorities, limiting generalizability across diverse populations. We did not capture communication, behavioral and clinical research not covered in a systematic/scoping review.

<sup>8</sup> Limitations: The PGen sample is subject to volunteer bias. Most participants bought a PGT product, so support for direct access is not surprising. Pathway participants were offered subsidized testing, so representation and selection bias may be enhanced. All survey research faces potential response bias. The questions are not directly comparable to other studies that worded items differently. Subjective responses may be subject to recall bias.

knowledge—thus not representative of the U.S. population. The authors wrote that “the misinterpretation that did occur may be magnified if PGT [personal genomic testing] expands out to sectors of the population with lower genetic knowledge and numeracy skills.” (Ostergren et al., 2015<sup>9</sup>)

The ability of DTC personal genomic testing to prompt health behavior change may be limited by the relatively small changes to risk perceived by recipients of these test results. (Carere et al., 2015<sup>10</sup>)

A 2013 review of studies of consumer views/experiences and surveys of relevant health care providers found that neither the health benefits envisioned by DTC genetic testing proponents (e.g., great improvements in positive health behavior) nor the worst fears of its critics (e.g., severe emotional distress, misunderstanding of results, burden on health system) had materialized. (Roberts et al., 2014<sup>11</sup>)

### **Polling Data Review**

Americans’ opinions of genetic testing were assessed most recently in an Associated Press/NORC poll (June 2018). Americans were interested in DNA testing to discover ancestry but skeptical of the tests’ ability to predict disease or guide medical treatment. Only 17% have had genetic testing, but over half of those who have not were interested in being tested. Motivations for testing included learning about their ethnic heritage (65%) and their children’s disease risk (39%). Although DTC testing company marketing budgets have increased, 54% of Americans said they have heard little or nothing about genetic testing.

In a poll from NPR-Truven (December 2017), just 29% said they or family members had considered genetic testing. Those most interested were under age 35. The top reason for testing was genealogy (30%). Of those tested through a doctor, the top reason was to help with a diagnosis (31%). Half of those who had been tested said a physician prescribed the test, while 49% ordered a DTC test. The number who had ordered a genetic test declined from 55% in a similar 2016 NPR-Truven poll to 47% in 2017.

A May 2017 survey found that DTC genetic test users were enthusiastic about expanded access to genetic testing (89.9%), and just 27.8% said they wanted increased government regulation. Users who sought testing to gauge disease risk were more supportive of incorporating genetic tests into medical care and less supportive of access to testing without medical professionals.

In July 2018, *Genetics in Medicine* published physicians’ perspectives on “unsolicited genomic results,” as more patients have begun taking DTC test results to their physicians. Doctors saw the need for clear, evidence-based paths for response and for clinical decision support. They worry about patients’ anxiety, false reassurance, lack of clinical utility, workflow issues and lack of payment for that work time.

A 2011 Yale-Syracuse-YouGov survey found that 65% of respondents agreed that “medical professionals should be involved in explaining test results,” which runs counter to practices of most DTC companies.

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<sup>9</sup> Limitations: Sample was not representative of the U.S. population. The test scenarios may have limitations: the comprehension scale was not formally validated; fewer items were used to test comprehension of pharmaco-genomic than disease and carrier status results; and the analysis did not explore how people understand their own test results.

<sup>10</sup> Limitations include potential selection bias. Responses could be influenced by baseline participant characteristics in ways that are not evident here. The study had limited ability to explore the impact of receiving an estimate of below-average cancer risk. Findings are not generalizable to other forms of genetic testing.

<sup>11</sup> Limitations: DTC genetic testing literature has overly relied on descriptive (vs. hypothesis-driven), atheoretical studies, convenience samples and mock test scenarios. Genetic testing literature has long shown incongruence in hypothetical vs. actual responses to testing. Literature from psychology suggests a tendency for people to overrate the intensity and duration of their emotional reaction to future events, such as receiving genetic risk information.

### III. Gene Editing

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#### Literature Review

The U.S. public supports gene editing for some uses (e.g., to improve health) but less so for boosting IQ, appearance or abilities, or for editing genes before birth other than to reduce risk of serious disease.

A major study, published in 2016, surveyed 12,500+ participants from 185 countries. It found overall support (59.0%) for “the use of gene editing in children and adults to cure life-threatening illnesses.” They also found support (59.4%) for “gene editing to cure debilitating diseases.” (The authors note these findings contrast with an earlier U.S.-Canada survey showing greater support for lifesaving purposes but less, for less severe disease.) In the 2016 study, 43.3% disagreed with gene editing for reasons other than health. Of those who agreed, when asked about specific traits, 68.0% supported gene editing to improve intelligence; 58.4%, to improve strength or athletic ability; and 51.3%, to modify appearance—all of which is consistent with earlier studies. On the impact of demographics, the authors write:

- “We did not find an association between self-reported wealth and support or resistance to gene editing in humans, but participants from countries with high Gross Domestic Product (GDP) per capita were generally more supportive of all health-related applications of gene editing ...”
- “We found a strong association between level of education and an increased acceptance of gene editing to treat diseases. Specifically, respondents who had completed tertiary education were 65% more likely to agree with gene editing for health-related purposes, compared to respondents who received no formal education.” (McCaughey et al., 2016<sup>12</sup>)

A new analysis, published in 2019, of the above data set found that “public resistance to human somatic or embryonic gene editing does not stem from an inherent mistrust of genome modification, but rather a desire for greater understanding.” Firm support existed for gene editing for health purposes in somatic and embryonic cells but low support for “eugenic manipulation.” (McCaughey et al., 2019<sup>13</sup>)

In a 2016 STAT-Harvard survey, only 35% of Americans supported therapeutic treatment of “unborn babies,” and a 2016 Pew Research Center poll found that only 31% were *not* worried by therapy that changed a baby’s genetic makeup and could be passed to future generations. In a 2016-2017 YouGov survey, 59% expressed some support for human genome editing to treat medical conditions or restore health, but only 39% expressed support for enhancing human abilities. Nearly half said gene editing was less acceptable if it “changed the genetic makeup of the whole population.” Two-thirds saw somatic (64%) and germline therapy (65%) as acceptable, but far fewer found germline (26%) and somatic enhancement (39%) acceptable. (Scheufele et al., 2017)

According to a 2016 analysis, “Over the course of the past 30 years, a majority of the public has expressed

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<sup>12</sup> Limitations/future research: Online surveys allow for rapid collation of opinions on a large scale; however, this approach has inherent limitations and recruitment biases. Translation into multiple languages may have introduced additional biases. Individuals were not examined for understanding of the concepts involved, so all respondents may not have fully comprehended the questions, potentially affecting data quality, so results should be interpreted with some caution. Future, population-based study could help explore the opinions of a specific population with fewer recruitment and selection biases, increasing generalizability of results. Qualitative research could allow more in-depth investigation of attitudes of under-represented demographic groups.

<sup>13</sup> Limitations: Results represent general trends across broad demographics; the demographic classifications used represent heterogeneous groups, whose motivations and influences cannot be captured with one open-ended question. Despite the large-scale collection enabled by online surveys, this method has limitations and recruitment biases, e.g., no exposure to people not on social media and, in this case, a gender bias favoring male respondents.



approval of gene therapy for improving the health of the person being treated, such as by curing a fatal or usually fatal disease (65 to 87%) or by reducing the risk of a fatal disease developing later in life (77 to 78%).” A majority also approve of gene editing to keep children from inheriting certain diseases, such as a usually fatal genetic disease (84%) or a non-fatal birth defect (66 to 77%). However, in this timeframe, majorities have not supported gene editing to improve intelligence (33 to 44% approve) or to enhance physical traits or appearance (25 to 44% approve). (Blendon et al., 2016<sup>14</sup>)

### **Polling Data Review**

A 2018 AP/NORC poll found that Americans favored gene editing to prevent disease or disability but strongly opposed gene technology to change appearance, intelligence, or athletic ability.

A 2018 Pew Research Center poll found that, despite some skepticism, most Americans expected gene editing to pave the way for medical advances that will benefit society as a whole (60% very/fairly likely).

A 2017 University of Wisconsin/YouGov poll in 2017 found that Americans think scientists should consult the public before applying gene editing to humans. The study’s author expected the public to draw a line at germline editing—edits that would be passed to future generations. However, support only dropped for editing for enhancement, rather than health. From a 2017 American Heart Association survey, scientists agreed that the public should be consulted before gene editing is used to treat human embryos.

Pew’s 2016 American Trends Research Panel found that Americans were more worried than enthusiastic about gene editing to change human capabilities. This poll asked “if *you* had a baby,” rather than any baby (48% definitely or probably would want gene editing to change human capabilities for “their” baby). On the morality of gene editing to give healthy babies a much-reduced risk of serious illness, 28% found it acceptable; 30% did not. Acceptability varied if the gene effects were not passed on to future generations (34% said more acceptable, 40% no difference). This finding was similar to Pew Research’s 2014 poll, where just 15% said changing genetic characteristics to make a baby more intelligent is an appropriate use of medical advances, and 46% said it would be appropriate to reduce risk of serious illness. (In this poll Pew asked about any baby, rather than asking respondents to consider their own baby.)

Last, a 2015 poll from the Wilson Center/Hart Research Associates found Americans to be ambivalent about precision genetic editing and that many supported a moratorium on human-based research.

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<sup>14</sup> Limitations/future research: Many of the relevant polling questions asked during the past three decades lack the precision that scientists might prefer; such imprecision suggests that many of the key issues are difficult for the public to understand. To obtain a full and accurate picture of the state of public opinion, we would need a level of public education that has not been achieved to date.

## IV. Concerns: Ethical, Privacy, Discrimination, Stigma, Psychological Harm

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### **Literature Review**

A review of 53 studies involving nearly 43,000 individuals found that respondents often conflated privacy, confidentiality, control and security—creating potential for confusion. Respondents were most concerned about use of their data by employers, insurers, and government; researchers were seen as trustworthy. Many were still willing to undergo genetic testing for research or their health care. Between protecting privacy and advancing research, two-thirds said research was more important. Respondents were rarely asked about re-identification risk. (Clayton et al., 2018<sup>15</sup>)

In a 2018 analysis of reviews on communication issues in cancer genetic testing (2010-2017), the top system-level barriers were concerns about privacy, insurance, and test cost. (Peterson et al., 2018<sup>16</sup>)

A 2008 survey of 4,659 U.S. adults found that privacy concerns varied by type of information, their degree of control over access, and potential for harm. African Americans, American Indians, and Alaska Natives, and members of two or more races were more likely to be concerned. While 90% had privacy concerns, less than half of those feared their data would be used against them. They worried more about government accessing their data than researchers; sharing data with pharmaceutical companies was even less palatable. The authors wrote, “For many people, concerns about privacy may not be an absolute deal-breaker that precludes participation in research but, rather, may be one of a list of several pros and cons that are weighed in deciding whether or not to participate.” (Kaufman et al., 2009<sup>17</sup>)

### **Polling Data Review**

In the December 2018 AP/NORC poll, 52% said the unethical use of gene editing is very likely, and 45% thought it very likely that gene editing will lead to unintended effects on human evolution. Cost was also a concern, as few think it likely most people will be able to afford the technology.

Americans were more likely to anticipate negative than positive effects from gene editing, according to a 2018 Pew Research Center poll. Americans were also skeptical that medical experts fully comprehend the health consequences of gene editing: only 36% say medical experts understand this very or fairly well. Americans also expected inequality to increase and that gene editing may only be available to the wealthy.

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<sup>15</sup> Future research: Future studies must conduct more in-depth investigations into which concerns about genetic privacy are most salient to people, the social forces that influence those concerns and the contexts that affect individuals’ decision making. It is critical to identify social practices that will make collection and use of these data more trustworthy for participants and patients—and to identify circumstances that lead people to set aside worries and decide to participate in research.

<sup>16</sup> Limitations: see footnote 7.

<sup>17</sup> Limitations/future research: Responses to a cross-sectional survey on participating in a hypothetical study will not necessarily correlate with actual behavior, so these results are likely not to be fully accurate in estimating actual genetic testing participation rates. This survey was fielded prior to passage of the Genetic Information Nondiscrimination Act of 2008. Actions that the public views as serious misuses of study data, the people whom they deem most likely to commit these actions, and what they believe could or should be done to improve public trust and prevent such actions all warrant further research. The effects of policy and scientific advances on public views of privacy risks associated with biobank or biomedical research participation warrant further investigation.

The Personalized Medicine Coalition found, in a May 2018 poll, that Americans' concerns about personalized medicine related to insurance coverage, costs, and potential discrimination. Most were not aware of the privacy protections in place to protect them from discrimination.

NPR-Truven polls found that the proportion of Americans with privacy concerns on genetic testing fell from 59% in 2016 to 47% in 2017.

A 2016 Pew Research Center focus group report assessed ways human enhancement could shape America's future. Many worried about biomedical advances boosting the capacities of healthy people, with contingent risks and potential for abuse. Views varied by the type of enhancement. A Pew Research 2014 poll found that only 15% support changing a baby's genes for enhancement.

Asked about expanding newborn screening to include genome sequencing, new parents were optimistic about potential benefits and limited harms likely to result; however, they voiced concerns about privacy and control over test results. (*Pediatrics*, 2016)

In a 2014 YouGov-Huffington Post poll, when Americans were asked how worried they were "that scientific research into human or animal DNA might lead to scientists 'playing god' with things that should remain outside the realm of science," 35% were very and 37% were somewhat worried. On research to produce children with higher intelligence or other special attributes, only 16% were in favor.

A 2009 study on privacy in biobank research, in *The American Journal of Human Genetics*, found that concerns may deter genetic research participation: 90% were concerned about privacy, 56% were concerned about researchers having their data, and 37% worried the data could be used against them.

## V. Racial & Ethnic Minority Populations

### Literature Review

A 2018 study noted "very little extant research in CGT [consumer genetic testing] in minority and underserved communities." (Peterson et al., 2018<sup>18</sup>) Studies identified for this ASHG review consistently found lower knowledge and awareness of genetic testing among racial/ethnic minorities. Minority populations had more concerns than non-Hispanic whites about genetic discrimination, stigma, or a poor medical prognosis but were willing to participate in genetic research nonetheless.

A 2019 review (1997-2017) found lower genetic testing awareness in non-whites, lower knowledge in Blacks and Latinos, and more genetic testing concerns among non-whites. (Canedo et al., 2019)

In nearly all studies noting differences by race or ethnicity, non-whites had more concerns about privacy, more desire for control over their data, and less willingness to share data. (Clayton et al., 2018<sup>19</sup>)

However, a 2019 study in persons of African descent found strong support for the importance of genetic research and willingness to participate in research, despite discrimination concerns (Scott et al., 2019<sup>20</sup>)

According to a 2018 analysis of HINTS data, non-Hispanic whites and Hispanics/Latinos were nearly at parity in awareness of DTC genetic testing in 2007; yet, while awareness in whites rose, Hispanics/Latinos stayed roughly the same. Awareness of DTC genetic testing was lower in racial/ethnic minorities and rural residents

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<sup>18</sup> Limitations: see footnote 7.

<sup>19</sup> Future research: see footnote 15.

<sup>20</sup> Future research: Further research on underlying reasons why persons of African descent choose to participate in genetic research should be explored and addressed to make research more inclusive and ethically sound.

than in non-Hispanic whites and urban residents. Awareness of genetic testing services among rural non-Hispanic whites was similar to that in urban minorities. (Apathy et al., 2018<sup>21</sup>)

A 2019 study in African Americans found concerns about specimen donation to biobanks: fear of their information being stolen or that specimens could be used for unintended purposes. (Reddy et al., 2019)

A review of 41 studies (2000-2015) showed low awareness and knowledge of genetic counselling and testing in African Americans, Asian Americans, and Hispanics. However, attitudes about genetic testing were generally positive, e.g., implications for their health and being able to inform family. Concerns included the emotional impact of test results, confidentiality, and discrimination. (Hann et al., 2017<sup>22</sup>)

A 2014 review found higher levels of suspicion among African Americans. African Americans and Latinos had less knowledge of genetic testing than whites and were less likely to have resources for it but had more interest in prenatal/adult testing than whites. African Americans were more concerned about discrimination, use of their information, and test costs. (Etchegary, 2014<sup>23</sup>)

### **Polling Data Review**

Public opinion polls on genetic research do not primarily examine racial differences. While most ask demographic questions on race, gender, etc., they did not always publish those data. A survey in *The American Journal of Human Genetics* in 2017 about biobank research consent and data sharing found that willingness to participate in such research was associated with self-identified white race.

## **VII. Gene Therapy: Pharmacogenomics & Personalized Medicine**

### **Literature Review**

A 2015 study of pharmacogenomics news stories found the “majority of articles over-stated the benefits of pharmacogenetic testing while paying less attention to the associated risks.” The authors wrote, “Of the 96 included articles, 95 (99%) stated at least one benefit for the application of PGx” (range of 1-7 per article). Benefits mentioned in the news stories included helping to establish personalized medicine (86% of articles examined), improving drug efficacy (61% of the articles), and improving drug safety (53% of articles). The risks mentioned in these same stories included adversely affecting the economic stability of the pharmaceutical industry (51% of articles examined), introducing discrimination into medical treatment (33% of articles), and loss of privacy and confidentiality for genetic data (24% of articles). (Almomani et al., 2015<sup>24</sup>)

In a literature analysis, whites were more likely to express interest in pharmacogenomic testing than African Americans. (Etchegary, 2014<sup>25</sup>) For example, in one study in that analysis (Diaz et al., 2014<sup>26</sup>), 34.3% of non-Hispanic whites (NHW) had heard of personalized medicine, vs. 27.8% of non-Hispanic blacks (NHB). For those unfamiliar with the term, once personalized medicine was explained to them, there were no statistically

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<sup>21</sup> Limitations: see footnote 5.

<sup>22</sup> Future research: More detailed research is needed in countries other than the U.S. and across a broader spectrum of ethnic minority groups.

<sup>23</sup> Limitations/future research: see footnote 1.

<sup>24</sup> Limitations: Generalizability of findings is limited since the analysis covered only higher-circulation newspapers. In the database used, copyrights prevent access to every article. The study was limited to newsprint media.

<sup>25</sup> Limitations/future research: see footnote 1.

<sup>26</sup> Limitations: This study relies on questions about behavioral intent and attitudes, not observed behaviors. This was a convenience sample, not randomly selected. It includes only individuals seen in a practice in South Carolina, which has a history of complex racial relations, so findings may not be generalizable to other areas of the U.S.

significant differences between the two groups in the perceived benefits of personalized medicine: prevention of diseases (79.5% NHW, 74.4% NHB), discovery of new treatments (82.2% NWH, 79.5% NHB), and improved family planning (65.8% NHW, 79.5% NHB).

### **Polling Data Review**

Personalized medicine was an unfamiliar concept to most Americans (71%), according to a November 2018 HealthDay/Harris poll. Of those who were familiar, nearly half (49%) do not understand that it can be more successful, with fewer side effects. Most (62%) did not realize it comes with a higher cost. Regardless of awareness, around half (48%) thought personalized medicine will lead to more successful treatment and fewer side effects. Americans were excited about personalized medicine's prospects.

A May 2018 Personalized Medicine Coalition poll found that, while most Americans were unfamiliar with personalized medicine, the majority wanted to learn more—matching a similar 2014 Coalition poll.

A 2012 survey on pharmacogenetic testing, in *Pharmacogenomics Journal*, found that Americans were interested in it to predict side effects (73%-85%), guide dosing (91%), and aid drug selection (92%). In another 2012 study in the journal, whites expressed positive views of pharmacogenetics for its ability to predict serious side effects.

## **VII. Epigenetics: Genetic Determinism, Genes-Environment Influences**

### **Literature Review**

While few studies addressed these topics, one interesting finding is that the U.S. public understood genetics concepts, such as pharmacogenetics and epigenetics, even when the terms were new to them.

The relationship between genetic determinism—the idea that genes are destiny—and knowledge and attitudes about genetics is unclear: “Perceptions of the relationship between genes and traits are not only rooted in people’s knowledge, but also in their values and social practices.” (Carver et al., 2017<sup>27</sup>)

In a broad literature analysis, the public seemed to understand that disease is not solely caused by genes but influenced by environmental and other causes, but the public did not show a clear understanding of gene-environment interaction or how genetic factors affected disease development. (Etchegary, 2014<sup>28</sup>)

### **Polling Data Review**

No polls were identified that addressed this topic.

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<sup>27</sup> Limitations/future research: Genetic determinism scales are often developed in context of particular topics or larger studies and are not likely to be very reliable alone; the authors advise others to use the determinism items in the Public Understanding and Attitudes towards Genetics and Genomics (PUGGS) questionnaire (described in this paper) along with its other sections. The questionnaire includes epigenetics items because, despite low current knowledge, they will allow future analyses of how well students understand contemporary genetics and genomics. Further studies are needed into the correlation of public attitudes about genomic technologies, knowledge of modern genetics and genomics, and deterministic thinking. The PUGGS questionnaire is generalizable to young adult populations with at least a high school education in most Western societies, but further studies are needed to validate it in other populations. More research is needed to analyze relationships between genetic determinism, genetics and genomics knowledge, and attitudes about genetic and genomic-based technologies, say, for use in science education. Multinational comparative studies may also be helpful.

<sup>28</sup> Limitations/future research: see footnote 1.

## VIII. Federal Funding of Genetics Research

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### **Literature Review**

Just two articles in this review mentioned public opinion on federal funding of genetic research.

In a 2014 study, 57% of Americans said they believe the federal government should spend more on genetic research (Almeling & Gadarian, 2014)

In a broad 2016 literature review, the authors reported that nearly two thirds (64%) of Americans said the U.S. government should fund scientific research on developing new gene-therapy treatments. While 44% thought the government should fund research on changing human genes before birth in order to reduce the risk of certain serious diseases, only 14% supported federal funding for research seeking to improve intelligence or physical traits of children. (Blendon et al., 2016<sup>29</sup>)

### **Polling Data Review**

The December 2018 AP/NORC poll asked whether Americans favored using taxpayer money to finance testing to develop gene editing technology. The poll used the phrase “testing on human embryos to develop gene-editing,” which resulted in 48% opposing and 26% favoring federal funding.

An older Yale/Syracuse/YouGov poll, from 2011, used more neutral language when asking about federal funding—and found that 57% believed the federal government should spend more on genetic research.

Federal funding of “research on changing genes of unborn babies” was a topic of two questions in a 2016 Harvard-STAT poll, with only 14% supporting such funding to improve intelligence or physical characteristics but 44% supporting federal funding to reduce risk of serious disease.

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<sup>29</sup> Limitations/future research: see footnote 14.

## CITATIONS

- Almeling, R., & Gadarian, S. K. (2014). Public opinion on policy issues in genetics and genomics. *Genetics in Medicine*, 16, 491-494. <https://doi.org/10.1038/gim.2013.175>
- Almomani, B., Hawwa, A. F., Goodfellow, N. A., Millership, J. S., McElnay, J. C. (2015). Pharmacogenetics and the print media: what is the public told? *BMC Medical Genetics*, 2015; 16: 32. <https://dx.doi.org/10.1186%2Fs12881-015-0172-3>
- Apathy, N. C., Menser, T., Keeran, L. M., Ford, E. W., Harle, C. A., Huerta, T. R. (2018). Trends and Gaps in Awareness of Direct-to-Consumer Genetic Tests from 2007 to 2014. *American Journal of Preventive Medicine*, 54(6):806-813. <https://doi.org/10.1016/j.amepre.2018.02.013>
- Blendon, R. J., Gorski, M. T., Benson, J. M. (2016). The Public and the Gene-Editing Revolution. *The New England Journal of Medicine*, 374(15):1406-1411. <https://doi.org/10.1056/NEJMp1602010>
- Canedo, J. R., Miller, S. T., Myers, H. F., Sanderson, M. (2019). Racial and ethnic differences in knowledge and attitudes about genetic testing in the US: Systematic review [Abstract]. *Journal of Genetic Counseling*, 28(3):587-601. <https://doi.org/10.1002/jgc4.1078>
- Carere, D. A., VanderWeele, T., Moreno, T. A., Mountain, J. L., Roberts, J. S., Kraft, P., ... PGen Study Group (2015). The impact of direct-to-consumer personal genomic testing on perceived risk of breast, prostate, colorectal, and lung cancer: findings from the PGen Study. *BMC Medical Genomics*, 8:63. <https://dx.doi.org/10.1186%2Fs12920-015-0140-y>
- Carver, R. B., Castera, J., Gericke, N., Menezes Evangelista, N. A., El-Hani, C. N. (2017). Young Adults' Belief in Genetic Determinism, and Knowledge and Attitudes towards Modern Genetics and Genomics: The PUGGS Questionnaire. *PLOS ONE*, 12(1): e0169808. <https://doi.org/10.1371/journal.pone.0169808>
- Caulfield, T. (2018). Spinning the Genome: Why Science Hype Matters. *Perspectives in Biology and Medicine*, 61(4):560-571. <https://doi.org/10.1353/pbm.2018.0065>
- Clayton, E. W., Halverson, C. M., Sathe, N. A., Malin, B. A. (2018). A systematic literature review of individuals' perspectives on privacy and genetic information in the United States. *PLOS ONE*, 13(10): e0204417. <https://doi.org/10.1371/journal.pone.0204417>
- Diaz, V. A., Mainous, A. G. 3<sup>rd</sup>, Gavin, J. K., Wilson, D. (2014). Racial differences in attitudes toward personalized medicine. *Public Health Genomics*, 17(1):1-6. <https://doi.org/10.1159/000354785>
- Dodson, D. S., Goldenberg, A. J., Davis, M. M., Singer, D. C., Tarini, B. A. (2015). Parent and Public Interest in Whole Genome Sequencing. *Public Health Genomics*, 18(3): 151–159. <https://dx.doi.org/10.1159%2F000375115>
- Etchegary, H. (2014). Public attitudes toward genetic risk testing and its role in healthcare. *Personalized Medicine*, 11(5):509-522. <https://doi.org/10.2217/pme.14.35>
- Fogleman, A. J., Zahnd, W. E., Lipka, A. E., Malhi, R. S., Ganai, S., Delfino, K. R., Jenkins, W. D. (2019). Knowledge, attitudes, and perceived barriers towards genetic testing across three rural Illinois communities. *Journal of Community Genetics*, 10(3): 417–423. <https://dx.doi.org/10.1007%2Fs12687-019-00407-w>
- Gollust, S. E., Gray, S. W., Carere, D. A., Koenig, B. A., Lehmann, L. S., McGuire, A. L., ... PGen Study Group (2017). Consumer Perspectives on Access to Direct-to-Consumer Genetic Testing: Role of Demographic Factors and the Testing Experience. *The Millbank Quarterly*, 95(2): 291–318. <https://dx.doi.org/10.1111%2F1468-0009.12262>
- Haga, S. B., Tindall, G., O'Daniel, J. M. (2012). Public Perspectives About Pharmacogenetic Testing and Managing Ancillary Findings. *Genetic Testing and Molecular Biomarkers*, 16(3): 193–197. <https://dx.doi.org/10.1089%2Fgtmb.2011.0118>
- Hann, K. E. J., Freeman, M., Fraser, L., Waller, J., Sanderson, S. C., Rahman, B., ... the PROMISE study team (2017). Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. *BMC Public Health*, 17: 503. <https://dx.doi.org/10.1186%2Fs12889-017-4375-8>

- Holton, A. E., Canary, H. E., Wong, B. (2017). Business and Breakthrough: Framing (Expanded) Genetic Carrier Screening for the Public. *Health Communication*, 32(9): 1051–1058. <https://dx.doi.org/10.1080%2F10410236.2016.1196515>
- Kaufman, D. J., Murphy-Bollinger, J., Scott, J., Hudson, K. L. (2009). Public Opinion about the Importance of Privacy in Biobank Research. *American Journal of Human Genetics*, 85(5): 643–654. <https://dx.doi.org/10.1016%2Fj.ajhg.2009.10.002>
- Lim, Q., McGill, B. C., Quinn, V. F., Tucker, K. M., Mizrahi, D., Patenaude, A. F., ... Wakefield, C. E. (2017). Parents' attitudes toward genetic testing of children for health conditions: A systematic review [Abstract]. *Clinical Genetics*, 92(6):569-578. <https://doi.org/10.1111/cge.12989>
- McCaughey, T., Sanfilippo, P. G., Gooden, G. E., Budden, D. M., Fan, L., Fenwick, E., ... Hewitt, A. W. (2016). A Global Social Media Survey of Attitudes to Human Genome Editing. *Cell Stem Cell*, 18(5):569-72. <https://doi.org/10.1016/j.stem.2016.04.011>
- McCaughey, T., Budden, D. M., Sanfilippo, P. G., Gooden, G. E. C., Fan, L., Fenwick, E., ... Hewitt, A. W. (2019). A Need for Better Understanding Is the Major Determinant for Public Perceptions of Human Gene Editing. *Human Gene Therapy*, 30(1):36-43. <https://doi.org/10.1089/hum.2018.033>
- Ostergren, J. E., Dingel, M. J., McCormick, J. B., Koenig, B. A., (2015). Unwarranted optimism in media portrayals of genetic research on addiction overshadows critical ethical and social concerns. *Journal of Health Communication*, 20(5): 555–565. <https://dx.doi.org/10.1080%2F10810730.2014.999895>
- Ostergren, J. E., Gornick, M. C., Carere, D. A., Kalia, S. S., Uhlmann, W. R., Ruffin, M. T., ... Roberts, J. S. (2015). How Well Do Customers of Direct-to-Consumer Personal Genomic Testing Services Comprehend Genetic Test Results? Findings from the Impact of Personal Genomics Study. *Public Health Genomics*, 18(4): 216–224. <https://dx.doi.org/10.1159%2F000431250>
- Peterson, E. B., Chou, W. S., Gaysynsky, A., Krakow, M., Elrick, A., Khoury, M. J., Kaphingst, K. A. (2018). Communication of cancer-related genetic and genomic information: A landscape analysis of reviews. *Translational Behavioral Medicine*, 8(1):59-70. <https://doi.org/10.1093/tbm/ibx063>
- Reddy, A., Amarnani, A., Chen, M., Dynes, S., Flores, B., Moshchinsky, A., ... Martello, L. (2019). Privacy Concerns About Personal Health Information and Fear of Unintended Use of Biospecimens Impact Donations by African American Patients. *Journal of Cancer Education*, 2019. <https://doi.org/10.1007/s13187-019-01491-9>
- Roberts, J. S., Ostergren, J. (2014). Direct-to-Consumer Genetic Testing and Personal Genomics Services: A Review of Recent Empirical Studies. *Current Genetic Medicine Reports*, 1(3): 182–200. <https://dx.doi.org/10.1007%2Fs40142-013-0018-2>
- Roberts, J. S., Gornick, M. C., Carere, D. A., Uhlmann, W. R., Ruffin, M. T., Green R. C., (2017). Direct-to-Consumer Genetic Testing: User Motivations, Decision Making, and Perceived Utility of Results. *Public Health Genomics*, 20(1):36-45. <https://doi.org/10.1159/000455006>
- Salloum, R. G., George, T. J., Silver, N., Markham, M. J., Hall, J. M., Guo, Y., ... Shenkman, E. A. (2018). Rural-urban and racial-ethnic differences in awareness of direct-to-consumer genetic testing. *BMC Public Health*, 18(1):277. <https://doi.org/10.1186/s12889-018-5190-6>
- Saylor, K. W., Ekunwe, L., Antoine-LaVigne, D., Sellers, D. E., McGraw, S., Levy, D., ... Joffe, S. (2019). Attitudes Toward Genetics and Genetic Testing Among Participants in the Jackson and Framingham Heart Studies. *Journal of Empirical Research on Human Research Ethics*, 14(3):262-273. <https://doi.org/10.1177/1556264619844851>
- Scheufele, D. A., Xenos, M. A., Howell, E. L., Rose, K. M., Brossard, D., Hardy, B. W. (2017). U.S. attitudes on human genome editing. *Science*, 357(6351), 553-554. <https://doi.org/10.1126/science.aan3708>
- Scott, D. M., Thomas, V. G., Otado, J., Rockcliffe, F., Olopoenia, O., Johnson, D., Callier, S. (2019). Attitudes and experiences regarding genetic research among persons of African descent. *Journal of Community Genetics*, 2019. <https://doi.org/10.1007/s12687-019-00422-x>



- Stewart, K. F. J., Wesseliuss, A., Schreurs, M. A. C., Schols, A. M. W. J., Zeegers, M. P. (2018). Behavioural changes, sharing behaviour and psychological responses after receiving direct-to-consumer genetic test results: a systematic review and meta-analysis. *Journal of Community Genetics*, 9(1):1-18. <https://doi.org/10.1007/s12687-017-0310-z>
- Stewart, K. F. J., Kokole, D., Wesseliuss, A., Schols, A. M. W. J., Zeegers, M. P., de Vries, H., van Osch, L. A. D. M. (2018). Factors Associated with Acceptability, Consideration and Intention of Uptake of Direct-to-Consumer Genetic Testing: A Survey Study. *Public Health Genomics*, 21(1-2):45-52. <https://doi.org/10.1159/000492960>

## ADDITIONAL REFERENCES

- Adams, I., Christopher, J., Williams, K. P., Sheppard, V. B. (2015). What Black Women Know and Want to Know About Counseling and Testing for BRCA 1/2. *Journal of Cancer Education*, 30(2):344-52. <https://doi.org/10.1007/s13187-014-0740-9>
- Agurs-Collins, T., Ferrer, R., Ottenbacher, A., Water, E. A., O'Connell, M. E., Hamilton, J. G. (2015). Public Awareness of Direct-to-Consumer Genetic Tests: Findings from the 2013 U.S. Health Information National Trends Survey [Abstract]. *Journal of Cancer Education*, 30(4):799-807. <https://doi.org/10.1007/s13187-014-0784-x>
- Allen, C. G., Andersen, B., Khoury, M. J., Roberts, M. C. (2018). Current Social Media Conversations about Genetics and Genomics in Health: A Twitter-Based Analysis. *Public Health Genomics*, 21(1-2):93-99. <https://doi.org/10.1159/000494381>
- Allum, N., Sibley, E., Sturgis, P., Stoneman, P. (2014). Religious beliefs, knowledge about science and attitudes towards medical genetics. *Public Understanding of Science*, 23(7):833-49. <https://doi.org/10.1177/0963662513492485>
- Bombard, Y., Miller, F. A., Hayeems, R. Z., Barg, C., Cressman, C., Carroll, J. C., ... Chakraborty, P. (2014). Public views on participating in newborn screening using genome sequencing [Abstract]. *European Journal of Human Genetics*, 22(11):1248-54. <https://doi.org/10.1038/ejhg.2014.22>
- Center for Genetics and Society. (2018). *CGS Summary of Public Opinion Polls*. Berkeley, CA: CGS Staff. Retrieved from <https://www.geneticsandsociety.org/internal-content/cgs-summary-public-opinion-polls>
- Cherkas, L. F., Harris, J. M., Levinson, E., Spector, T. D., Prainsack, B. (2010). A Survey of UK Public Interest in Internet-Based Personal Genome Testing. *PLOS ONE*, 5(10): e13473. <https://dx.doi.org/10.1371/journal.pone.0013473>
- Covolo, L., Rubinelli, S., Ceretti, E., Gelatti, U. (2015). Internet-Based Direct-to-Consumer Genetic Testing: A Systematic Review. *Journal of Medical Internet Research*, 17(12):e279. <https://doi.org/10.2196/jmir.4378>
- Critchley, C., Nicol, D., Otlowski, M., Chalmers, D. (2015). Public reaction to direct-to-consumer online genetic tests: Comparing attitudes, trust and intentions across commercial and conventional providers [Abstract]. *Public Understanding of Science*, 24(6):731-50. <https://doi.org/10.1177/0963662513519937>
- Critchley, C., Nicol, D., McWhirter, R. (2017). Identifying public expectations of genetic biobanks [Abstract]. *Public Understanding of Science*, 26(6):671-687. <https://doi.org/10.1177/0963662515623925>
- Daud, A. N. A., Bergsma, E. L., Bergman, J. E. H., De Walle, H. E. K., Kerstjens-Frederikse, W. S., Bijker, B. J., ... Wilffert, B. (2017). Knowledge and attitude regarding pharmacogenomics among formerly pregnant women in the Netherlands and their interest in pharmacogenetic research. *BMC Pregnancy Childbirth*, 17(1):120. <https://doi.org/10.1186/s12884-017-1290-z>
- Dijkstra, A. M., Schuijff, M. (2016). Public opinions about human enhancement can enhance the expert-only debate: A review study. *Public Understanding of Science*, 25(5), 588-602. <https://doi.org/10.1177/0963662514566748>
- Dye, T., Li, D., Demment, M., Groth, S., Fernandez, D., Dozier, A., Chang, J. (2016). Sociocultural variation in attitudes toward use of genetic information and participation in genetic research by race in the United States: implications for precision medicine. *Journal of the American Medical Informatics Association*, 23(4):782-6. <https://doi.org/10.1093/jamia/ocv214>
- Etchegary, H., Green, J., Parfrey, P., Street, C., Pullman, D. (2015). Community engagement with genetics: public perceptions and expectations about genetics research. *Health Expectations*, 18(5):1413-25. <https://doi.org/10.1111/hex.12122>

- Haga, S. B., Barry, W. T., Mills, R., Ginsburg, G. S., Svetkey, L., Sullivan, J., Willard, H. F. (2013). Public Knowledge of and Attitudes Toward Genetics and Genetic Testing. *Genetic Testing and Molecular Biomarkers*, 17(4):327-35. <https://doi.org/10.1089/gtmb.2012.0350>
- Hamilton, J. G., Shuk, E., Arniella, G., Gonzalez, C. J., Gold, G. S., Gany, F., ... Hay, J. L. (2016). Genetic Testing Awareness and Attitudes among Latinos: Exploring Shared Perceptions and Gender-Based Differences. *Public Health Genomics*, 19(1):34-46. <https://doi.org/10.1159/000441552>
- Harvard Kennedy School. (2018). Direct-to-consumer genetic testing: Research review. *Journalist's Resource*. Cambridge, MA: Reichel, C. Retrieved from <https://journalistsresource.org/studies/government/health-care/direct-to-consumer-genetic-testing/>.
- Henneman, L., Timmermans, D. R., van der Wal, G. (2004). Public experiences, knowledge and expectations about medical genetics and the use of genetic information [Abstract]. *Community Genetics*, 7(1):33-43. <https://doi.org/10.1159/000080302>
- Henneman, L., Vermeulen, E., van El, C. G., Claassen, L., Timmermans, D. R., Cornel, M. C. (2013). Public attitudes towards genetic testing revisited: comparing opinions between 2002 and 2010. *European Journal of Human Genetics*, 21(8):793-9. <https://doi.org/10.1038/ejhg.2012.271>
- Holton, A. E., Canary, H. E., Wong, B. (2017). Business and Breakthrough: Framing (Expanded) Genetic Carrier Screening for the Public. *Health Communication*, 32(9):1051-1058. <https://doi.org/10.1080/10410236.2016.1196515>
- Johannessen, J., Nærlund, T., Bloss, C., Rietschel, M., Strohmaier, J., Gjevik, E., ... Andreassen, O. A. (2016). Parents' attitudes toward genetic research in autism spectrum disorder [Abstract]. *Psychiatric Genetics*, 26(2):74-80. <https://doi.org/10.1097/YPG.0000000000000121>
- Kaphingst, K. A., McBride, C. M., Wade, C., Alford, S. H., Brody, L. C., Baxevanis, A. D. (2010). Consumers' Use of Web-Based Information and Their Decisions About Multiplex Genetic Susceptibility Testing. *Journal of Medical Internet Research*, 12(3): e41. <https://dx.doi.org/10.2196%2Fjmir.1587>
- Kaphingst, K. A., McBride, C. M., Wade, C., Alford, S. H., Reid, R., Larson, E., ... Brody, L. C. (2012). Patients' understanding of and responses to multiplex genetic susceptibility test results. *Genetics in Medicine*, 14(7):681-7. <https://doi.org/10.1038/gim.2012.22>
- Kaphingst, K. A., Stafford, J. D., McGowan, L. D., Seo, J., Lachance, C. R., Goodman, M. S. (2015). Effects of racial and ethnic group and health literacy on responses to genomic risk information in a medically underserved population. *Health Psychology*, 34(2):101-10. <https://doi.org/10.1037/hea0000177>
- Kelly, S. E., Farrimond, H. R. (2012). Non-invasive prenatal genetic testing: a study of public attitudes [Abstract]. *Public Health Genomics*, 15(2):73-81. <https://doi.org/10.1159/000331254>
- Kerath, S. M., Klein, G., Kern, M., Shapira, I., Witthuhn, J., Norohna, N., ... Taioli, E. (2013). Beliefs and attitudes towards participating in genetic research—a population based cross-sectional study [Abstract]. *BMC Public Health*, 13:114. <https://doi.org/10.1186/1471-2458-13-114>
- Kulchak, R. A., Bailey, L., Fultz, K., Fan, A., Williams, J. L., Buchanan, A., ... Williams, M. S. (2018). Parental attitudes and expectations towards receiving genetic test results in healthy children [Abstract]. *Translational Behavioral Medicine*, 8(1):44-53. <https://doi.org/10.1093/tbm/ibx044>
- Laskey, S. L., Williams, J., Pierre-Louis, J., O'Riordan, M., Matthews, A., Robin, N. H. (2003). Attitudes of African American premedical students toward genetic testing and screening [Abstract]. *Genetics in Medicine*, 5(1):49-54. <https://doi.org/10.1097/00125817-200301000-00008>
- Lautenbach, D. M., Christensen, K. D., Sparks, J. A., Green, R. C. (2013). Communicating Genetic Risk Information for Common Disorders in the Era of Genomic Medicine. *Annual Review of Genomics and Human Genetics*, 14:491-513. <https://doi.org/10.1146/annurev-genom-092010-110722>
- Lea, D. H., Kaphingst, K. A., Bowen, D., Lipkus, I., Hadley, D. W. (2011). Communicating Genetic and Genomic Information: Health Literacy and Numeracy Considerations. *Public Health Genomics*, 14(4-5):279-89. <https://doi.org/10.1159/000294191>

- Lipkus, I. M. (2007). Numeric, Verbal and Visual Formats of Conveying Health Risks: Suggested Best Practices and Future Recommendations. *Medical Decision Making*, 27(5):696-713. <https://doi.org/10.1177/0272989X07307271>
- Marks, N. J. (2014). Speech acts and performances of scientific citizenship: Examining how scientists talk about therapeutic cloning. *Public Understanding of Science*, 23(5):494-510. <https://doi.org/10.1177/0963662512451969>
- Meisel, S. F., Rahman, B., Side, L., Fraser, L., Gessler, S., Lanceley, A. (2016). Genetic testing and personalized ovarian cancer screening: a survey of public attitudes. *BMC Women's Health*, 16: 46. <https://dx.doi.org/10.1186%2Fs12905-016-0325-3>
- Morgenstern, J., Hegele, R. A., Nisker, J. (2015). Simple genetics language as source of miscommunication between genetics researchers and potential research participants and potential research participants in informed consent documents. *Public Understanding of Science*, 24(6):751-66. <https://doi.org/10.1177/0963662514528439>
- Nelson, S. C., Crouch, J. M., Bamshad, M. J., Tabor, H. K., Yu, J. H. (2016). Use of metaphors about exome and whole genome sequencing [Abstract]. *American Journal of Medical Genetics-Part A*, 170A(5):1127-33. <https://doi.org/10.1002/ajmg.a.37571>
- Okita, T., Ohashi, N., Kabata, D., Shintani, A., Kato, K. (2018). Public attitudes in Japan toward participation in whole genome sequencing studies [Abstract]. *Human Genomics*, 12(1):21. <https://doi.org/10.1186/s40246-018-0153-7>
- Peters, E., Hibbard, J., Slovic, P., Dieckmann, N. (2007). Numeracy Skill and The Communication, Comprehension, and Use of Risk-Benefit Information. *Health Affairs*, 26(3):741-8. <https://doi.org/10.1377/hlthaff.26.3.741>
- Peterson, E. B., Chou, W. S., Gaysynsky, A., Krakow, M., Elrick, A., Khoury, M. J., Kaphingst, K. A. (2018). Communication of cancer-related genetic and genomic information: A landscape analysis of reviews. *Translational Behavioral Medicine*, 8(1):59-70. <https://doi.org/10.1093/tbm/ibx063>
- Petty, C. M., McSweeney, J. C., Stewart, K. E., Price, E. T., Cleves, M. A., Heo, S., Souder, E. (2015). Perceptions of family history and genetic testing and feasibility of pedigree development among African Americans with hypertension. *European Journal of Cardiovascular Nursing*, 14(1):8-15. <https://doi.org/10.1177/1474515114556198>
- Pew Research Center. (2018). *Public Views of Gene Editing for Babies Depend on How It Would Be Used*. Washington, DC: Funk, C., Hefferon, M. Retrieved from <https://www.pewresearch.org/science/2018/08/16/most-americans-accept-genetic-engineering-of-animals-that-benefits-human-health-but-many-oppose-other-uses/>
- Roberts, L. W., Kim, J. P. (2017). Receptiveness to participation in genetic research: A pilot study comparing views of people with depression, diabetes, or no illness [Abstract]. *Journal of Psychiatric Research*, 94:156-162. <https://doi.org/10.1016/j.jpsychires.2017.07.002>
- Robillard, J. M. (2015). Communicating in context: a priority for gene therapy researchers. *Expert Opinion on Biological Therapy*, 15(3), 315-318. <https://doi.org/10.1517/14712598.2015.1001735>
- Roy, M., Rivest, M. P., Namian, D., Moreau, N. (2019). The critical reception of the DSM-5: Towards a typology of audiences [Abstract]. *Public Understanding of Science*, 963662519868969. <https://doi.org/10.1177/0963662519868969>
- Ruhrmann, G., Guenther, L., Kessler, S. H., Milde, J. (2015). Frames of scientific evidence: How journalists represent the (un)certainly of molecular medicine in science television programs [Abstract]. *Public Understanding of Science*, 24(6):681-96. <https://doi.org/10.1177/0963662513510643>
- Ryan, K. A., De Vries, R. G., Uhlmann, W. R., Roberts, J. S., Gornick, M. C. (2017). Public's Views toward Return of Secondary Results in Genomic Sequencing: It's (Almost) All About the Choice. *Journal of Genetic Counseling*, 26(6):1197-1212. <https://doi.org/10.1007/s10897-017-0095-6>
- Samuel, G. N., Farsides, B. (2018). Genomics England's implementation of its public engagement strategy: Blurred boundaries between engagement for the United Kingdom's 100,000 Genomes project and the need for public support. *Public Understanding of Science*, 27(3):352-364. <https://doi.org/10.1177/0963662517747200>
- Sanderson, S. C., Wardle, J., Jarvis, M. J., Humphries, S. E. (2004). Public interest in genetic testing for susceptibility to heart disease and cancer: a population-based survey in the UK [Abstract]. *Preventive Medicine*, 39(3):458-64. <https://doi.org/10.1016/j.ypped.2004.04.051>

- Sanderson, S. C., Wardle, J., Michie, S. (2005). The effects of a genetic information leaflet on public attitudes towards genetic testing [Abstract]. *Public Understanding of Science*, 14(2):213-24. <https://doi.org/10.1177/0963662505050993>
- Sanderson, S. C., Brothers, K. B., Mercaldo, N. D., Clayton, E. W., Antommara, A. H. M., Aufox, S. A., ... Holm, I. A. (2017). Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-Site Experimental Survey in the US. *American Journal of Human Genetics*, 100(3):414-427. <https://doi.org/10.1016/j.ajhg.2017.01.021>
- Schaper, M., Wöhlke, S., Schicktanz, S. (2019). "I would rather have it done by a doctor"—laypeople's perceptions of direct-to-consumer genetic testing (DTC-GT) and its ethical implications [Abstract]. *Medicine, Health Care and Philosophy*, 22(1):31–40. <https://doi.org/10.1007/s11019-018-9837-y>
- Schwarz-Plaschg, C. (2018). Nanotechnology is like ... The rhetorical roles of analogies in public engagement [Abstract]. *Public Understanding of Science*, 27(2):153-167. <https://doi.org/10.1177%2F0963662516655686>
- Shavers, V. L., Lynch, C. F., Burmeister, L. F. (2002). Racial differences in factors that influence the willingness to participate in medical research studies [Abstract]. *Annals of Epidemiology*, 12(4):248-56. [http://dx.doi.org/10.1016/S1047-2797\(01\)00265-4](http://dx.doi.org/10.1016/S1047-2797(01)00265-4)
- Steinbach, R. J., Allyse, M., Michie, M., Liu, E. Y., Cho, M. K. (2016). "This Lifetime Commitment": Public Conceptions of Disability and Noninvasive Prenatal Genetic Screening [Abstract]. *American Journal of Medical Genetics*, 170A(2): 363–374. <https://dx.doi.org/10.1002%2Fajmg.a.37459>
- Stewart, K. F. J., Kokole, D., Wesselius, A., Schols, A. M. W. J., Zeegers, M. P., de Vries, H., van Osch, L. A. D. M. (2018). Factors Associated with Acceptability, Consideration and Intention of Uptake of Direct-to-Consumer Genetic Testing: A Survey Study. *Public Health Genomics*, 21(1-2):45-52. <https://doi.org/10.1159/000492960>
- Taylor, S. (2011). A population-based survey in Australia of men's and women's perceptions of genetic risk and predictive genetic testing and implications for primary care [Abstract]. *Public Health Genomics*, 14(6):325-36. <https://doi.org/10.1159/000324706>
- Tercyak, K. P., Bronheim, S. M., Kahn, N., Robertson, H. A., Anthony, B. J., Mays, D., ... DeMarco, T. A. (2019). Cancer genetic health communication in families tested for hereditary breast/ovarian cancer risk: a qualitative investigation of impact on children's genetic health literacy and psychosocial adjustment [Abstract]. *Translational Behavioral Medicine*, 9(3), 493–503. <https://doi.org/10.1093/tbm/ibz012>
- Vayena, E., Ineichen, C., Stoupka, E., Hafen, E. (2014). Playing a part in research? University students' attitudes to direct-to-consumer genomics [Abstract]. *Public Health Genomics*, 17(3):158-68. <https://doi.org/10.1159/000360257>
- Vermeulen, E., Henneman, L., van El, C. G., Cornel, M. C. (2014). Public attitudes towards preventive genomics and personal interest in genetic testing to prevent disease: a survey study [Abstract]. *European Journal of Public Health*, 24(5):768-75. <https://doi.org/10.1093/eurpub/ckt143>
- Voorwinden, J. S., Buitenhuis, A. H., Birnie, E., Lucassen, A. M., Verkerk, M. A., van Langen, I. M., ... Ranchor, A. V. (2017). Expanded carrier screening: what determines intended participation and can this be influenced by message framing and narrative information? *European Journal of Human Genetics*, 25(7):793-800. <https://doi.org/10.1038/ejhg.2017.74>
- Waters, E. A., Ball, L., Gehlert, S. (2017). "I don't believe it." Acceptance and skepticism of genetic health information among African-American and White smokers. *Social Science & Medicine*, 184:153-160. <https://doi.org/10.1016/j.socscimed.2017.04.053>
- Wilde, A., Meiser, B., Mitchell, P. B., Schofield, P. R. (2010). Public interest in predictive genetic testing, including direct-to-consumer testing, for susceptibility to major depression; preliminary findings [Abstract]. *European Journal of Human Genetics*, 18(1):47-51. <https://doi.org/10.1038/ejhg.2009.138>