AP® RESEARCH
2016 SCORING GUIDELINES

AP Research Performance Task Rubric: Academic Paper

Content Area	Performance Levels		
1 Understand and Analyze Context	The paper identifies the topic of inquiry. 2	The paper identifies the topic, and describes the purpose and focus of the inquiry. 4	The paper explains the topic, purpose, and focus of the inquiry and why further investigation of the topic is needed by connecting it to the larger discipline, field, and/or scholarly community. 6
2 Understand and Analyze Argument	The paper identifies or cites previous works and/or summarizes a single perspective on the student's topic of inquiry. 2	The paper summarizes, individually, previous works representing multiple perspectives about the student's topic of inquiry. 4	The paper explains the relationships among multiple works representing multiple perspectives, describing the connection to the student's topic of inquiry. 6
3 Evaluate Sources and Evidence	The paper uses sources/evidence that are unsubstantiated as relevant and/or credible for the purpose of the inquiry. 2	The paper uses credible and relevant sources/evidence suited to the purpose of the inquiry. 4	The paper explains the relevance and significance of the used sources/cited evidence by connecting them to the student's topic of inquiry. 6
4 Research Design	The paper presents a summary of the approach, method, or process, but the summary is oversimplified. 3	The paper describes in detail the approach, method, or process. 5	The paper provides a logical rationale by explaining the alignment between the chosen approach, method, or process and the research question/project goal. 7
5 Establish Argument	The paper presents an argument, conclusion or understanding, but it is simplistic or inconsistent, and/or it provides unsupported or illogical links between the evidence and the claim(s). 3	The paper presents an argument, conclusion, or new understanding that the paper justifies by explaining the links between evidence with claims. 5	The paper presents an argument, conclusion or new understanding that acknowledges and explains the consequences and implications in context. 7
6 Select and Use Evidence	Evidence is presented, but it is insufficient or sometimes inconsistent in supporting the paper's conclusion or understanding. 2	The paper supports its conclusion through the compilation of relevant and sufficient evidence. 4	The paper demonstrates a compelling argument through effective interpretation and synthesis of the evidence and through describing its relevance and significance. 6
7 Engage Audience	Organizational and design elements are present, but sometimes distract from communication or are superfluous. 1	Organizational and design elements convey the paper's message. 2	Organizational and design elements engage the audience, effectively emphasize the paper's message and demonstrate the credibility of the writer. 3
8 Apply Conventions	The paper cites and attributes the work of others, but does so inconsistently and/or incorrectly. 2	The paper consistently and accurately cites and attributes the work of others. 4	The paper effectively integrates the knowledge and ideas of others and consistently distinguishes between the student's voice and that of others. 6

AP® RESEARCH
2016 SCORING GUIDELINES

9 Apply Conventions	The paper's use of grammar, style and mechanics convey the student's ideas; however, errors interfere with communication and/or credibility. 1	The paper's word choice and syntax adheres to established conventions of grammar, usage and mechanics. There may be some errors, but they do not interfere with the author's meaning. 2	The paper's word choice and syntax enhances communication through variety, emphasis, and precision. 3

NOTE: To receive the highest performance level presumes that the student also achieved the preceding performance levels in that row.

ADDITIONAL SCORES: In addition to the scores represented on the rubric, readers can also assign scores of **0** (zero).

- A score of **0** is assigned to a single row of the rubric when the paper displays a below-minimum level of quality as identified in that row of the rubric.

AP® RESEARCH
2016 SCORING COMMENTARY

Academic Paper

Overview

This performance task was intended to assess students' ability to conduct scholarly and responsible research and articulate an evidence-based argument that clearly communicates the conclusion, solution, or answer to their stated research question. More specifically, this performance task was intended to assess students' ability to:

- Generate a focused research question that is situated within or connected to a larger scholarly context or community;
- Explore relationships between and among multiple works representing multiple perspectives within the scholarly literature related to the topic of inquiry;
- Articulate what approach, method, or process they have chosen to use to address their research question, why they have chosen that approach, and how they employed it;
- Develop and present their own argument, conclusion, or new understanding;
- Support their conclusion through the compilation, use, and synthesis of relevant and significant evidence;
- Use organizational and design elements to effectively convey the paper's message;
- Consistently and accurately cite, attribute, and integrate the knowledge and work of others, while distinguishing between the student's voice and that of others;
- Generate a paper in which word choice and syntax enhance communication by adhering to established conventions of grammar, usage, and mechanics.

Special Considerations Concerning Genetic Testing in Minority Populations and Ethnicities

April 15, 2016

Abstract

The potential special impacts of genetic testing on minorities are considered using a qualitative research approach. Using a review of studies on genetic testing and studies on health care issues for minorities, areas of concern were established as possible sources of a discrepancy in the impact of genetic testing between minority and majority populations. The most important areas of concern were identified to be access and cost of health care, public education about genetic testing, and security of databases with genetic information. Policies centered on specific populations, access to health care facilities and professionals, flow of information to the consumer, and security of databases are recommended to abate this troubling discrepancy.

Special Considerations Concerning Genetic Testing in Minority Populations and Ethnicities

Introduction

Genetic testing and sequencing is a suite of new technologies that allows a scientist or medical professional to peer into the molecular sequence that defines every one of our inherited traits. Currently, the technology is used in three distinct contexts: targeted testing for a particular marker, general genome sequencing and testing, and for identification purposes (U.S. National Library of Medicine, 2016). Each of these contexts presents special ethical problems not seen in other medical fields. Genetic sequence work can reveal tens of thousands of outcomes, many of which cannot be anticipated before the test. For example, a mutated BRCA gene may indicate greatly increased chance of breast cancer (Ford, Easton, Bishop, Narod, & Goldgar, 1994). Even directly testing for this gene could result in personal, familial, and other problems. Thus, evaluating benefits and drawbacks of a genetic test can be much more complex than a traditional test, or can even be impossible. This study begins with a discussion of the various concerns with genetic testing. Minorities, with unique genetic health concerns, such as high susceptibility to genetic disease and unique genetic markers, may be at a greater risk for the adverse impacts of DNA testing. This study aims to identify solutions to reconcile this disparity between minorities and others.

Literature Review

Introduction

Because this study is a meta-analysis of the current literature on the bioethics of genetic testing and minorities in the medical system, a cursory review of the literature is presented here to examine the categories and terms used in the study. In Methods, studies used in the meta-analysis will be examined more closely.

Targeted genetic testing

Targeted genetic testing is used to identify whether a pre-specified genetic marker, such as the BRCA gene, is present in a person's DNA. These markers are specific sequences of nucleotides that are associated with a particular phenotype (such as increased chance of breast cancer). This is the oldest form of genetic testing. In this process, a DNA sample is taken from a subject and compared molecularly to a strand of DNA that matches the target sequence (de Gonzalez, Berg, Visvanathan, & Robson, 2009). The results simply are positive or negative.

Targeted genetic testing is used to test for a variety of specific and well-documented genetic variations. For example, it is possible to test for presence of the BRCA1 gene, which indicate an 87% chance of breast cancer and 44% chance of ovarian cancer before 70 years of age (Ford, Easton, Bishop, Narod, & Goldgar, 1994). This trait could be passed on to one's offspring. It also informs a patient that s/he should receive more frequent mammograms, as they become more useful and effective as the risk of breast cancer increases (de Gonzalez, Berg, Visvanathan, & Robson, 2009).

Targeted genetic testing can also be used to test for a recessive genetic marker which could appear in one's offspring. For example, sickle-cell anemia appears only with the presence of two recessive alleles. Prospective parents who have some family history of sickle-cell anemia could test for the presence of one recessive genetic marker. If both test positive, there is a one in

four chance that their child will have sickle-cell anemia, which can be life-threatening in children if initially undetected ("What Is Sickle Cell," 2015).

General genome sequencing

General genome sequencing is a relatively new technology in which a patient is tested for a very wide range of traits. This can either consist essentially of repeated targeted testing, or it can use more modern technology which detects the entire molecular sequence of the DNA and uses data from the Human Genome Project to identify the phenotypical meaning of each segment. This allows a person to identify *any* potential disease marker or other genetic trait. For example, a person might find out that they have a high chance for a disease they did not even know about (23andMe, Inc, 2016). In many cases, this has a positive health impact, as it can facilitate the early detection of many diseases and cancers. It can also test for many genetic diseases for which there is no cure yet.

General genome sequencing can also be used for ancestry and familial purposes as well. Consumer genetic services like 23andMe can determine what portion of a person's ancestry comes from each region of the world, and it can also be used as a paternity test.

Genetic testing for identification

Genetic testing is also often used for the purposes of identifying a person from a DNA sample. This method often uses a superficial way of testing the DNA, such as restriction fragment polymorphism. This method allows a person to compare two DNA samples without determining the actual molecular sequence of the DNA. This is very useful for law enforcement purposes, where DNA from a crime scene can be used to place a particular person there (Carracedo, Salas, Pestoni, Lareu, & Guillén, 2000). For this purpose, many countries have laws

that require felons to submit a DNA sample to law enforcement as both a deterrent from future crime and to help solve current cases (Giannelli, 1997). DNA evidence has also exonerated a number of people imprisoned, especially for rape (The Innocence Project, 2016). Restriction fragment analysis is does not provide phenotypical information, and as such it cannot be used alone to identify a person in the way a genome sequence can. However, law enforcement agencies have recently begun to store DNA in a way that could be later tested for the precise sequence (Carracedo, Salas, Pestoni, Lareu, & Guillén, 2000).

Special Ethics for Genetic Testing

Genetic testing may cause ethical and other concerns (Di Pietro, Giuli, & Spagnolo, 2004; Foster & Sharp, 2006). As with any medical test, there must be an analysis of the benefits and drawbacks before it is administered. For genetic testing, however, this presents a unique problem because there are a vastly greater number of possible test outcomes, particularly with full genome sequencing. A mammogram either reveals breast cancer or does not, and there can be either false positives or false negatives. The complex analysis of benefits and drawbacks of DNA testing can make it impossible to determine whether a test is worthwhile. The principles and problems behind this complexity are discussed below.

Confidentiality and Identification

Genetic information is very sensitive for a number of reasons. Insurance companies, employers, and other entities have incentives to know a person's disease risk, as well as other information that genetics may reveal in the future. The Genetic Information Nondiscrimination Act of 2008 supposedly prevents discrimination using genetic data, but case studies of its effects

have been limited or nonexistent (McGuire & Majumder, 2009). Family members might have an interest in knowing the results of a genetic test for the purposes of progeny or end of life planning. Due to the high sensitivity of genetic information, genetic testing companies such as 23andMe have extensive and complex privacy policies that are difficult for the usual consumer to understand. Furthermore, databases that these companies hold could be vulnerable to attacks as modern encryption and security techniques become progressively weaker (Cox, 2014).

Law enforcement DNA databases present human rights issues, as they are often taken from arrestees, not necessarily people who have committed a crime. Also, the databases that police hold are apparently a target of many recent cyberattacks (Bray, 2015).

DNA identification in supposedly anonymous studies is also a concern. Some "anonymized" human genomes have been released, but people have been able to discover the identity of their donor using phenotypic information (Sample, 2005). This presents a problem with data publication in such studies.

Consent and Diseases

Two important and related aspects of the DNA testing process are consent and disease risk analysis. DNA testing is unique because it often reveals susceptibility or inevitability of a disease well before a cure is available (Barlow-Stewart & Burnett, 2006). In some scenarios, this information could also be completely unexpected (23andMe, Inc, 2016). For example, a genetic sequence could reveal an allele for Huntington's Disease, a neurodegenerative disorder which does not appear until a person's early 40s. Knowing that Huntington's is imminent is usually not considered useful and can even harm the patient. Thus, it is very important that the patient

provides informed consent: indication that s/he understands the risk of disease identification, even when there may be no cure (Bennett, n.d.).

Testing of Children

Related to the *consent* category is concern about the testing of children. Children are at a unique disadvantage in genetic testing because they do not make consent-related decisions (i.e. their parents do), yet the impact of genetic knowledge will last for the rest of their lives. As a result, doctors usually do not administer DNA tests for children except for targeted tests or for the purpose of identification (Barlow-Stewart & Burnett, 2006).

Limitations of Tests

Another important concern about DNA testing is ensuring that patient and doctor is aware of the limitations of DNA testing. In the media, DNA testing and sequencing is often presented as an omniscient, exhaustive test in the media, yet many diseases and other indicators are heavily influenced by environmental factors as well as genetics (U.S. National Library of Medicine, 2016). Furthermore, the genetics of most human traits are not yet fully understood. This means that a genetic test cannot predict the day when a person will develop cancer or what their intelligence quotient is, for example.

Family Dynamics and Duty to Inform

Lastly, DNA testing can cause a number of issues and ethical dilemmas in families. For example, if a mother tests positive for the BRCA2 breast cancer risk factor, is she obligated to inform her daughters? Is she obligated to take the test in the first place so her daughters can find out if they are at risk? What if a person, using a consumer DNA product, inadvertently discovers that their father is not their biological father? These can lead to serious social and familial

problems. Genetic counselors often deal specifically with familial issues with DNA testing and sequencing.

Minorities and the medical system

Minorities have a special relationship with the medical system. Generally, they have increased risk of many diseases (Cooper, 2004), yet many minorities have reduced access to healthcare facilities (US Department of Health and Human Services, 2010). Current efforts to bring more medical services to minority populations may still keep care at a lower quality for minorities than for the rest of the population ("Health Coverage by Race," 2013). Therefore, minorities are a unique concern for the purposes of genetic testing. The lack of access and other factors could impact the decisions surrounding genetic testing.

Also, minorities often have increased interaction with law enforcement (LaFraniere & Lehren, 2015), raising concerns about the collection of DNA as a regular law enforcement protocol. Could this practice disproportionately impact minorities?

Furthermore, scientific studies may be less sensitive to the cultural concerns about genetics and minorities than with the general population. This study aims to identify whether these special considerations negatively impact minorities in a disproportionate way.

Methods

This research employed a qualitative approach with some tenets of a phenomenological study. It aimed not to establish any cause-and-effect relationship as a quantitative approach would; it rather establishes direction for policy decisions based on a synthesis of available quantitative and qualitative studies and evidence. These policy decisions can occur at a wide selection of levels, from lawmakers and executives to hospitals and doctors.

The first segment of the research characterized and described the nature of minority-specific issues with personal DNA sequencing. A collection of different studies, articles, and opinion pieces from reputable scientists were collected. Studies and articles were selected based primarily on relevance; list of studies and reasons for inclusion are in Table 1. The share of attention given to each topic in a predetermined list was recorded for each article. Topics were chosen using the categories of concern presented in Barlow-Stewart & Burnett, 2006: *patient identification*, *consent* (including incurable disease), *limitations of testing*, *testing of children*, and *duty to inform* (including relatives). Confidentiality was lumped with patient identification. To obtain a general view of concerns about genetic testing, the portions of attention given to each topic were averaged over all the works. These values are presented in Table 2. Articles with substantial scientific research and articles that also gave attention to racial disparities were weighted twice as heavily in the average, as explained in Table 1 below.

List of Studies

Study or Work	**Weight**	**Description and Rationale**
Lewis, 2012	1	This PLoS blog post by Ricki Lewis describes why she chooses not to have her genome sequenced. It outlines specific areas of concern and provides reasons for them. While it is a blog post, it was written by a reputable scientist and appears in a reputable source.
Carracedo, Salas, Pestoni, Lareu, & Guillén, 2000	1	This study examines the challenges associated with DNA databases, particularly for forensics. It is a high-quality study in the *Journal of Medical Ethics*, but only receives a weight of 1 because it only covers the law enforcement use of DNA testing.
Di Pietro, Giuli, & Spagnolo, 2004	2	This paper in *Annals of Oncology* specifically covers the ethical concern of testing for BRCA

		in patients. The principles discussed, however, can be extended to many other genetic traits. The study also discusses the sensitivities to race that genetic testing has. Because it is very relevant and highly reputable, it receives a weight of 2.
Foster & Sharp, 2006	2	This study in *Human Molecular Genetics* examines the overall impacts of genetic testing. It covers a wide variety of impacts, including a short discussion of the dangers with race and stigmatization. The breadth of this study earns it a weight of 2.
Henderson, 2013	1	This article in *The Guardian* is a synthesis of any recent studies in the bioethics of genetic testing. While it is not original research in a journal, it is in a reputable newspaper and offers a more public opinion on the dangers of genetic testing and sequencing.
Murphy, 2004	2	*Case Studies in Biomedical Research Ethics* is a seminal work in the field of bioethics. It is used as a textbook in many college courses. For this study, the chapter on genetic sequencing and testing was examined. Its status as a classic work in this field earns it a weight of 2.
Barlow-Stewart & Burnett, 2006	N/A	This study was used to define the categories of concern with which to examine the other studies. It offers little depth or original research, but it covers a range of topics, making it appropriate to define the categories listed in the next table. It appeared in *The Clinical Biochemical Review* in 2006.

Table 1. Studies and other works included in review

The priorities identified from the average of studies were compared to a list of minority-specific issues (listed under results), especially those identified in the same articles that

were factored into the averages. Areas of conceptual overlap were identified and ranked based on the amount of conceptual overlap and the value from averaging the studies from Table 2.

After description and elucidation of the problem with DNA sequencing and minorities, the results were be interpreted and routes to solutions were be examined. The most effective solutions that solve the widest selection of problems will be gathered. The impacts of these potential solutions were assessed and the routes to achieve them were recommended (see Summary of Solutions).

Findings from Review

Concerns about genetic testing

Patient identification/confidentiality	31.30%
Consent (including concern about incurable disease)	41.30%
Understanding the limitations of the tests	15.00%
Testing of children	2.22%
Duty to inform/Relatives	10.19%

Table 2. Proportion of areas of concern among bioethical studies and texts concerning genetic testing. Note that percentages do not add to 100.00% due to rounding.

The results of this study include two different sets of data and observation. The first is the proportion of concerns about genetic testing in the scientific community. These data will be used to identify the most pressing problems in DNA sequencing and testing that are affecting and will affect different populations. The second set of data is a list of concerns about minorities in health care situations in general. This list is unranked, and the issues will be given equal value in analysis because the minority-specific concerns may be population-specific, while the genetic

testing concerns are not. This study intends to help all minorities, and ranking specific concerns based on prevalence may leave the concerns of some small minorities out.

As noted in methods, these data were gleaned generally from qualitative scientific studies that examined the issues pertaining to genetic sequencing and testing. All of the sources were either published in a peer-review journal or were authored by a well-known and respected author *and* had specific anecdotes, experiences, or interviews about the issues at hand.

The categories for the first data set were selected based on an article published in 2006 in *The Clinical Biochemist Reviews* (Barlow-Stewart & Burnett, 2006). They were edited slightly to correspond to a wider range of concerns. Notably, the patient identification and confidentiality categories were combined due to their similarity.

As can be discerned in Table 2, there were widely varying amounts of emphasis on each category of concern about genetic sequencing.

The most important category was *patient consent*, including concerns about incurable disease, as 41.3% of the concern fell under this category. Studies very frequently emphasized the importance of informed consent, which means that a person is fully aware of the possible benefits, drawbacks, and effects of a genetic test. This includes making sure that the person knows that genetic testing may reveal diseases for which there is no cure.

Next, there was also concern about *patient identification/confidentiality*, making up 31.3% of the concern. Especially in settings where the patient feels compelled to test his or her DNA, such as in a family with a history of the BRCA2 gene, there is concern that the genetic information could be disclosed to insurers or other family members without permission. In

addition, patient identification in supposedly anonymous studies is a frequently mentioned concern.

15% of the concern surrounded *understanding the limitations of the tests*. This is typically expressed as a communications issue between the doctor and the patient or the outside world (e.g. the media). The doctor or researcher must be sure to disclose that a genetic test usually does not predict with certainty, that many diseases are multifactorial and often involve a combination of genes and environmental factors to materialize. Also, the media could become misinformed, reporting that genetic testing is absolute and not probabilistic, as it has in the past (ICTMN Staff, 2011).

Only 10.1% of the concern surrounded the *duty to report to relatives* and other people the results of genetic sequencing or testing. There was relatively little discussion surrounding the social and familial dynamics with DNA testing, for example moral dilemmas that may arise with a positive test for the BRCA1/2 genes, where a person might feel obligated to tell their family about the results.

Lastly, *testing of children* factored into the concern only at 2.2%. Concerns in this category are related to *consent* concerns, where an individual may later regret that his or her parents consented to DNA testing at a young age. This result may be very low in part because DNA testing of children is not prevalent today (Barlow-Stewart & Burnett, 2006).

Evaluating the concerns pertaining to health care and minorities yielded 6 principal categories of concern from two sources (U.S. Department of Health and Human Services, 2010; Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). These are listed in Table 3. These allow comparisons and matches to be made between the specific genetic concerns and the broad

concerns about minorities. The specifics of each category and how they interact with the genetic testing concerns is discussed below.

Concerns about minorities

1	Access to healthcare and facilities
2	Cost of services, especially in disadvantaged communities.
3	Discrimination in provision of services and insurance against minorities
4	Disproportionate effects of diseases among some diseases and populations
5	Stereotyping and stigmatization among the general population; public perspectives
6	Identification of cultural-specific concerns in research

Table 3. Principal concerns surrounding minorities and health care (U.S. Department of Health and Human Services, 2010; Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003)

Discussion

This study aimed to determine whether minorities are at a disadvantage relating to the special ethical implications of DNA testing and sequencing. Here, each of the more important patient concerns from Table 2 is compared with the minority-specific healthcare concerns in Table 3.

Consent and Incurable Diseases

The most important problem with DNA testing was found to be consent, especially as it relates to incurable disease. This problem interacts primarily with the access and cost issues with healthcare in minorities.

For example, personal genetic sequencing services such as 23andMe are most effective and safest when used with the consultation with a doctor or genetic counselor. People in minority communities, on average, do not have as much access to these types of specialized practitioners

as people in other communities do. Even in places where these practitioners are available, cost is often prohibitive and can be more of a barrier to minorities ("Health Coverage by Race," 2013). These gaps will lead to a discrepancy in adverse effects of these tests: minorities will be more severely impacted.

Possible solutions to the access and cost problems include mandating that primary care physicians must be trained in some genetic counseling, so that they can provide advice to their patients. Education efforts about the possible adverse results of genetic testing and sequencing could also improve the situation.

Patient Identification and Confidentiality

Patient identification and confidentiality concerns also interact with the minority-specific healthcare concerns. Minority patients who elect to have their DNA sequenced or tested using consumer products or in a study may be at a higher risk of identification. This is due to many minority-specific markers that significantly narrow identification of genetic patients. This issue could amount to cultural insensitivity in scientific studies of minority DNA.

While not a healthcare-specific concern, patient identification also presents issues with law enforcement DNA protocols. Because minorities are overrepresented in both arrests and false arrests (Hartney & Vuong, 2009), any adverse impact of DNA in law enforcement databases would disproportionately affect minority populations.

The problems with patient identification can be alleviated for all populations with increased security on DNA databases and anonymity of DNA studies. Routes to these solutions are discussed below.

Understanding the Limitations of the Tests

Patients are usually educated about the limitations of genetic sequencing and testing by their genetic counselor or doctor, so people without access to these resources are at a disadvantage. Therefore, the understanding limitations category of concern has similar interactions with minority healthcare concerns as the first category. Both access and cost are disproportionate barriers to minority patients in understanding the limitations of genetic testing and sequencing (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003).

As noted above, access and cost issues could be alleviated by mandating genetic counseling training in primary care physicians, and by public educational efforts. Legislation will also play an important role in ensuring that patients are properly educated before performing a genetic test.

Other Areas of Concern

The other categories of concern (*duty to inform relatives* and *testing of children*) were not of great enough concern to warrant consideration in relation to minorities. It is also worth noting that both of these categories are closely related to the *consent* category, so related solutions will also apply to them.

Limitations

This study was performed using a qualitative research approach, so there are resultant limitations to consider. While it may suggest future quantitative studies, this study cannot establish a cause and effect relationship as would a quantitative study of this material. It intends to avoid overlap with a would-be quantitative study by focusing on the categorical rather than the specific.

In particular, this study does not independently establish the underlying causes of the discrepancy between minority and majority populations in relation to genetic testing. It only identifies that the problem exists and suggests possible solutions based on areas of previous concern. For this reason, a previous review of the literature included studies that establish a connection between minority populations and health care coverage issues. In order to cure the larger, underlying problem with minorities and health care, these studies should be used in place of this one. This study suggests solutions that treat only the symptoms of concern about genetic testing.

This study should not overlap with a quantitative study of this material due to its categorical nature. While this analysis was performed using a the relative importance of different categories of concern, the absolute importance of each category is not established. For example, this study did not have the means to discover what percentage of minority adults have had negative or harmful experiences with genetic testing. However, it did establish that a categorical discrepancy exists between minority populations and the majority.

The implications of this study should be limited to the solutions suggested in the next section. While it is intended to be a policy recommendation, this study should not be viewed in isolation, without the support of quantitative analyses on this topic.

Conclusion

This study addressed the problem with genetic sequencing disproportionately affecting minorities. In a review of literature on minority health care coverage and on genetic testing, areas of overlap were established. This study found the categories of concern about genetic testing that

are of the greatest concern to minorities. Here, viable solutions are offered to address each of the categories of concern. Synthesizing from the above analysis, there are a few approaches to medical and other policy that will help to alleviate these disproportionate impacts of genetic testing and sequencing on minorities. These include improving access to professional genetic advice, improved public education and information about genetic testing and sequencing, and increased security of genetic databases.

Access to Health Care

Access to health care in minority populations in the United States is an issue even without the impact of genetic testing and sequencing ("Health Coverage by Race," 2013). Impediments to access exist at the “organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels”, making this a particularly formidable problem (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). Lack of insurance is a concern with these populations, but recently the Affordable Care Act has improved the racial gap in health insurance coverage ("Health Coverage by Race," 2013). Breaking down other barriers to health care, especially social ones such as language and neighborhood access to healthcare, will be paramount to increasing access. These issues pertain most significantly to Hispanic Americans, but they also apply to other populations (US Department of Health and Human Services, 2010).

According to the Brookings Institute, policy to improve minority health care access should include individualized target populations, as this is the most effective way to improve access and quality of coverage. Broad interventions too often makes little advancement towards its goals. The Brookings Institute also suggests that interventions need to be integrated at the

multiple levels of service and policy: laws, facilities, and doctors. Comparative effectiveness research (CER) is needed to address which approaches are appropriate for specific circumstances and populations (Brennan et al., 2009).

Cost of Health Care

The cost of health care is a particular issue relating to access. While recent legislation, such as the Affordable Care Act, has improved costs, the United States still has one of the most expensive healthcare systems in the developed world . Increased efficiency in the health care system, particularly at the institutional level, will help to bring costs back in line with other countries (Kane, 2012). However, a more synoptic solution of governmental subsidization of costs is included in the Affordable Care Act, so cost should become less a personal problem than a national problem ("Health Coverage by Race," 2013). This will remove the burden from the minorities to meet the cost of American health care. Therefore, policy should focus more on the social aspects of access.

Public education on genetic testing and sequencing

Public education specific to the risks of genetic testing will be important as genetic testing technology becomes more prevalent in the consumer realm. Education efforts about a particular medical product or procedure can occur at either the product level (for example, information packets about an MRI) or the societal level (for example, advertising against cigarette use). For the time being, society-level education would not be a cost-effective way to target the small percentage of the population that uses genetic testing (U.S. National Library of Medicine, 2016). Therefore, product-level education is the most important. Laws to mandate this education could include a mandatory consultation with a doctor about the realities of genetic

testing prior to use. Also, information about the personal risks of genetic testing should be included on or in all packaging of consumer sequencing products.

Proper care with databases of genetic information

Security of personal genetic data with minorities particularly in mind will become a necessary measure to prevent theft of genetic data. Because law enforcement databases will hold a disproportionate number of minority DNA samples due to institutional police bias (Lin & Harris, 2009; LaFraniere & Lehren, 2015), special care must be taken to protect these databases from recent cyberattacks on their data (Bray, 2015). Failure to protect that data will expose minorities to a societal risk of DNA data theft due to minorities' overrepresentation. Additionally, police practices should be revised to decrease the arrest discrepancy with minorities, which will decrease the DNA collection discrepancy with minorities, as DNA is typically taken upon arrest.

The most important minority-specific step would be to ensure confidentiality of minority specific sequences and markers that could lead to the identification of a minority patient. This will allow minority patients to have more equal footing with the general population in both DNA databases and research publications.

Genetic testing will be an extremely useful resource for the medical and consumer worlds. By understanding the impact it will have on all populations, we can begin to regulate this rapidly-growing industry proactively. The measures recommended here will keep the negative impacts on minorities to a minimum. This will keep the impacts on the population as a whole equal and positive.

References

23andMe, Inc. (2015). How it works. Retrieved September 3, 2015, from 23andMe website: https://www.23andme.com/howitworks/

Bangemann, M., & al., E. (1994, May 16). *Recommendations to the European Council Europe and the global information society*. Retrieved February 8, 2016, from Channeling Reality website: http://channelingreality.com/Digital_Treason/Brussels_1995/Bangemann_report.pdf

Barlow-Stewart, K., & Burnett, L. (2006). Ethical considerations in the use of DNA for the diagnosis of diseases. *The Clinical Biochemist Reviews*, *27*(1), 53-61. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1390792/

Bennett, R. L. (n.d.). *Testing for Huntington's disease: Making an informed choice* [Pamphlet]. Retrieved from https://depts.washington.edu/neurolog/images/neurogenetics/hungtinton.pdf

Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, *118*, 293-302. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497553/pdf/12815076.pdf

Branch, C., & Fraserirector, I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*, *57*(4), 181-217. http://dx.doi.org/10.1177/1077558700574009

Bray, H. (2015, April 6). When hackers cripple data, police departments pay ransom. Retrieved February 8, 2016, from The Boston Globe website: https://www.bostonglobe.com/business/2015/04/06/tewksbury-police-pay-bitcoin-ransom-hackers/PkcE1GBTOfU52p31F9FM5L/story.html

Brennan, N., Cafarella, N., Kocot, S. L., McKethan, A., Morrison, M., Nguyen, N., . . . Williams, R. D., II. (2009, August). Improving quality and value in the U.S. health care system. Retrieved March 28, 2016, from The Brookings Institute website: http://www.brookings.edu/research/reports/2009/08/21-bpc-qualityreport

Carracedo, A., Salas, A., Pestoni, C., Lareu, M. V., & Guillén, M. (2000). Ethical-legal problems of DNA databases in criminal investigation. *Journal of Medical Ethics*, *26*(4), 266-271. http://dx.doi.org/10.1136/jme.26.4.266

Cooper, R. S. (2004). Genetic factors in ethnic disparities in health. In N. B. Anderson, R. A. Butatao, & B. Cohen (Eds.), *National Research Council (US) panel on race, ethnicity, and health in later life*. Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK25517/

Cox, J. (2014, September 18). Your encryption will be useless against hackers with quantum computers. Retrieved February 8, 2016, from Motherboard website: http://motherboard.vice.com/read/your-encryption-will-be-useless-against-hackers-with-quantum-computers

de Gonzalez, A. B., Berg, C. D., Visvanathan, K., & Robson, M. Estimating risk of radiation-induced breast cancer from mammographic screening for young BRCA mutation carriers. Journal of the National Cancer Institute, 2009; 101: 205-209.

Di Pietro, M. L., Giuli, A., & Spagnolo, A. G. (2004). Ethical implications of predictive DNA testing for hereditary breast cancer. *Annals of Oncology*, (15), i65-i70. http://dx.doi.org/10.1093/annonc/mdh662

Faden, R. R. (June 01, 2004). Bioethics: A Field in Transition. *The Journal of Law, Medicine & Ethics, 32,* 2, 276-278.

Ford, D., Easton, D. F., Bishop, D. T., Narod, S. A., & Goldgar, D. E. (1994). Risks of cancer in BRCA1-mutation carriers [Abstract]. *The Lancet*, *343*(8899), 692-695. http://dx.doi.org/10.1016/S0140-6736(94)91578-4

Foster, M. W., & Sharp, R. R. (2006). Ethical issues in medical-sequencing research: Implications of genotype–phenotype studies for individuals and populations. *Human Molecular Genetics*, *15*(1), R45-R49. http://dx.doi.org/10.1093/hmg/ddl049

Giannelli, P. C. (1997). *Criminal discovery, scientific evidence, and DNA* [Brochure]. Retrieved from http://scholarlycommons.law.case.edu/cgi/viewcontent.cgi?article=1358&context=faculty_publications

Graham-Rowe, D. (2016, February 17). USB stick can sequence DNA in seconds. Retrieved September 3, 2015, from New Scientist website: https://www.newscientist.com/article/dn21495-usb-stick-can-sequence-dna-in-seconds/

Hartney, C., & Vuong, L. (2009). *Created equal: Racial and ethnic disparities in the US criminal justice system* [Pamphlet]. Retrieved from http://www.nccdglobal.org/sites/default/files/publication_pdf/created-equal.pdf

Health coverage by race and ethnicity: The potential impact of the Affordable Care Act. (2013, March 13). Retrieved November 1, 2015, from The Henry J. Kaiser Family Foundation website: http://kff.org/disparities-policy/issue-brief/health-coverage-by-race-and-ethnicity-the-potential-impact-of-the-affordable-care-act/

Henderson, M. (2013, September 9). Human genome sequencing: The real ethical dilemmas. Retrieved September 3, 2015, from The Gaurdian website: http://www.theguardian.com/science/2013/sep/09/genetics-ethics-human-gene-sequencing

High-Level Group on the Information Society. (n.d.). *Recommendations to the European Council: Europe and the global information society* [Pamphlet]. Retrieved from http://channelingreality.com/Digital_Treason/Brussels_1995/Bangemann_report.pdf

ICTMN Staff. (2011, April 12). What DNA can tell you and what it can't. Retrieved March 30, 2016, from Indian Country Today Media Network website: http://indiancountrytodaymedianetwork.com/2011/04/12/what-dna-can-tell-you-and-what-it-cant-27849

Illumina, Inc. (2016). Human whole-genome sequencing services. Retrieved February 8, 2016, from Illumina website: http://www.illumina.com/services/whole-genome-sequencing-services.html

The Innocence Project. (2016, March 17). DNA exonerations nationwide. Retrieved March 30, 2016, from The Innocence Project website: http://www.innocenceproject.org/free-innocent/improve-the-law/fact-sheets/dna-exonerations-nationwide

Kane, J. (2012, October 22). Health costs: How the U.S. compares with other countries. Retrieved March 30, 2016, from PBS Newshour website: http://www.pbs.org/newshour/rundown/health-costs-how-the-us-compares-with-other-countries/

Kurcher, M., & Kelso, J. (2010). High-throughput DNA sequencing – concepts and limitations. *Bioessays*, (32), 524-536. <https://web.archive.org/web/20140505164611/http://www.genetics.iastate.edu/workNGS_Kircher_BioEssays10.pdf>

LaFraniere, S., & Lehren, A. W. (2015, October 24). The disproportionate risks of driving while black. Retrieved February 8, 2016, from The New York Times website: http://www.nytimes.com/2015/10/25/us/racial-disparity-traffic-stops-driving-black.html

Lewis, R. (2012, November 1). Why I Don't Want to Know My Genome Sequence [Blog post]. Retrieved from DNA Science Blog: http://blogs.plos.org/dnascience/2012/11/01/why-i-dont-want-to-know-my-genome-sequence/

Lin, A. C., & Harris, D. R. (Eds.). (2009, January). The colors of poverty: Why racial & ethnic disparities persist. Retrieved February 8, 2016, from National Poverty Center website: http://www.npc.umich.edu/publications/policy_briefs/brief16/

McGuire, A. L., & Majumder, M. A. (2009). Two cheers for GINA? *Genome Medicine*, *1*(1), 6. http://dx.doi.org/10.1186/gm6

Murphy, T. F. (2004). *Case studies in biomedical research ethics*. Cambridge, MA: MIT Press.

Norrgard, K. (2008). Forensics, DNA fingerprinting, and CODIS. *Nature Education*, *1*(1), 35. Retrieved from http://www.nature.com/scitable/topicpage/forensics-dna-fingerprinting-and-codis-736

Sample, I. (2005, November 2). Teenager finds sperm donor dad on internet. Retrieved March 28, 2016, from The Gaurdian website: https://www.theguardian.com/science/2005/nov/03/genetics.news

Shelton, T. (2014, January 14). Preterm birth by Filipino women linked to genetic mutational change. Retrieved February 8, 2016, from University of Hawai'i website: http://www.hawaii.edu/news/2014/01/14/preterm-birth-by-filipino-women-linked-to-genetic-mutational-change/

U.S. Department of Health and Human Services. (2010). Disparities in healthcare quality among racial and ethnic minority groups. Retrieved March 30, 2016, from Agency for Healthcare Research and Quality website: http://archive.ahrq.gov/research/findings/nhqrdr/nhqrdr10/minority.html

U.S. National Library of Medicine. (2016, March 21). What are the risks and limitations of genetic testing? Retrieved March 28, 2016, from Genetics Home Reference website: https://ghr.nlm.nih.gov/handbook/testing/riskslimitations

U.S. National Library of Medicine. (2016, March 21). What are the types of genetic tests? Retrieved March 28, 2016, from Genetics Home Reference website: https://ghr.nlm.nih.gov/handbook/testing/uses

U.S. National Library of Medicine. (2016, March 28). Genetic Testing. Retrieved March 30, 2016, from Genetics Home Reference website: https://ghr.nlm.nih.gov/handbook/testing?show=all

Wade, N. (2015, March 29). Scientists Seek Ban on Method of Editing the Human Genome. Retrieved September 3, 2015, from The New York Times website: http://www.nytimes.com/2015/03/20/science/biologists-call-for-halt-to-gene-editing-technique-in-humans.html?_r=0

Werner-Lin, A. (2010). Building the cancer family: Family planning in the context of inherited breast and ovarian cancer risk. *Journal of the Society for Social Work and Research*, *1*(1), 14-27. http://dx.doi.org/10.5243/jsswr.2010.3

What is sickle cell disease? (2015, June 12). Retrieved November 1, 2015, from National Heart, Lung, and Blood Institute website: http://www.nhlbi.nih.gov/health/health-topics/topics/sca/

Wilcox, A. J., Taylor, J. A., Sharpe, R. R., & London, S. J. (1999). Genetic determinism and the overprotection of human subjects. *Nature Genetics*, *21*, 362. http://dx.doi.org/10.1038/7692

AP® RESEARCH
2016 SCORING COMMENTARY

Academic Paper

Sample: G
Content Area: Understand and Analyze Context — Row 1 Score: 6
Content Area: Understand and Analyze Argument — Row 2 Score: 6
Content Area: Evaluate Sources and Evidence — Row 3 Score: 6
Content Area: Research Design — Row 4 Score: 7
Content Area: Establish Argument — Row 5 Score: 7
Content Area: Select and Use Evidence — Row 6 Score: 6
Content Area: Engage Audience — Row 7 Score: 3
Content Area: Apply Conventions — Row 8 Score: 6
Content Area: Apply Conventions — Row 9 Score: 3

HIGH SAMPLE RESPONSE

"Special Considerations Concerning Genetic Testing in Minority Populations and Ethnicities"

Content Area: Understand and Analyze Context — Row 1
The response earned 6 points on this row because it explains the high stakes of genetic testing and why it is particularly relevant for members of minority communities who are at risk for genetic disease. The inquiry connects to the current state of the science of genetic testing throughout the Literature Review. See page 9, where particular considerations for minorities regarding genetic testing are explained.

Content Area: Understand and Analyze Argument — Row 2
The response earned 6 points on this row because it explains several ethical concerns and how they might be balanced with benefits of genetic testing (i.e., multiple perspectives in dialogue with one another) through an examination of current scholarly literature in the field. The literature is connected to the student's inquiry because the paper raises specific questions about how genetic testing might disproportionately impact minority communities.

Content Area: Evaluate Sources and Evidence — Row 3
The response earned 6 points on this row because topics gleaned from the Literature Review form the basis for themes of the meta-analysis. Sources used in the Literature Review (and bibliography) are scholarly and/or relevant to the inquiry (academic journals, public health research, etc.).

Content Area: Research Design — Row 4
The response earned 7 points on this row because the method of meta-analysis is explained in detail, and the paper makes the case for meta-analysis as the right approach for the inquiry. See page 10 for student's explanation of how sources were selected for the meta-analysis.

Content Area: Establish Argument — Row 5
The response earned 7 points on this row because it provides new understanding of the disproportionate concerns of minority communities regarding genetic testing and even makes several specific policy recommendations in the Conclusion section (pp. 18–21), from the need to address costs (p. 20) to the necessity of safeguarding databases of genetic information (p. 21), all based on evidence from the meta-analysis. It discusses limitations of meta-analysis as an approach (pp. 17–18).

AP® RESEARCH
2016 SCORING COMMENTARY

Academic Paper

Content Area: Select and Use Evidence — Row 6
The response earned 6 points on this row because evidence from the meta-analysis is compiled and analyzed to make policy recommendations (pp. 18–21). The evidence regarding various concerns about genetic testing are synthesized to show relationships among them (e.g., high costs are related to limited access), and feasible solutions to each of the problems are suggested.

Content Area: Engage Audience — Row 7
The response earned 3 points on this row because tables are used well to show the methodology and findings (pp. 10–12, p. 15), and they are referenced in the text; each section is labeled appropriately. These organizational designs help readers navigate and understand a complex argument.

Content Area: Apply Conventions — Row 8
The response earned 6 points on this row because it moves smoothly between other scholars' points and its own argument. See page 13, where the student explains how data were gleaned from the qualitative studies and then categorized for this study. The student's voice comes through clearly and is in control of the material, especially in the Findings from Review section (pp. 12–15). Citations enhance the student's own argument rather than driving the argument.

Content Area: Apply Conventions — Row 9
The response earned 3 points on this row because it makes a complex topic both accessible and engaging through sophisticated syntax and vocabulary. The argument flows smoothly right through to its conclusions.