

Score row	Total number of points earned: 39 (out of 42 possible points)	Scoring Commentary
IWA-1	6	Well defined and focused research question; the relationship of the question to the source materials does not seem to be clearly articulated.
IWA-2	6	The essay discusses both pros and cons of genetic mapping.
IWA-3	6	The argument interprets and synthesizes evidence from a wide range of sources, from Christian magazines to the NIH. The use of the largest medical library as a source seems a bit off as does the use of a Canadian source for the US nondiscrimination act.
IWA-4	6	The essay attempts to describe the credentials of the sources but some do not seem appropriate such as suing the NIH for discrimination regarding its funding practices or citing a PHD as lending credibility.
IWA-5	6	The argument is well organized and well reasoned for the most part. Some conclusions such as genetic testing on children or keeping genetic mapping results between doctor and patient were inferred by writer's interpretation of the evidence.
IWA-6	4	The argument links claims and evidence and makes connections between them. Occasionally extraneous information that is not directly related is used; for example the firing of a woman for needing expensive medicine really did not have anything to do with an employer giving a potential employee a genetic mapping test to anticipate the cost of insurance or types of drugs for Alzheimer's disease.
IWA-7	3	Citations seem adequate; reference section at end has incomplete statements that would not be useful to the reader but footnoted citations provide the information.
IWA-8	2	Run on sentences occur periodically; paragraphs not always driven by a topic sentence.

Ethical and Legal Implications of Genetic Mapping

For some time, doctors have known that family history played a role in the illnesses that a person contracted, but they didn't believe anything could really be done with that information besides medical surveillance, which is the periodic review of a person's health status. Now, when a person is concerned about inheriting certain illnesses that may run in their family, they can be "genetically mapped." Genetic mapping is a method that is used to determine the location of and relative distances between genes on a chromosome. Basically, this confirms whether or not you are likely to contract a certain illness. Candidates could include individuals who are pregnant or are considering having a child and are at risk for giving birth to a child with a genetic defect, or a person who may be at risk for certain types of cancer. Examples of genetic screenings are embryo/fetal which tests for genetic defects such as Down Syndrome, neonatal which tests for PKU (phenylketonuria), carrier screenings to determine if people are carriers for certain genetic defects, and testing for economic reasons which would be insurance companies or employers using genetic information to make coverage or hiring decisions. Genetic mapping can help a person prepare for or prevent a disease. But, along with the medical advances and positive effects that genomic mapping brings, there are many implications that accompany the positive consequences, such as ethical and legal perspectives. What are the ethical and legal implications of genetic mapping and do they outweigh the benefits of genetic mapping?

The Human Genome Project was initiated in the United States by the National Institutes of Health and the Department of Energy in 1990. The Human Genome Project is an international research effort that determined the DNA sequence of the human genome (the entirety of an organism's hereditary information).¹ Completed in April of 2003, it gave us the ability to read nature's complete genetic blueprint for building a human being. The project took 15 years and was \$3 billion federally funded². In February of 2011, *Nature* magazine published the National Human Genome Research Institute's strategic plan for the future of human genome research. This plan was called "Charting a course for genomic medicine from base pairs to bedside." According to the National Institutes of Health News, which has been accused of racial bias against African Americans by only funding 16% of grants submitted by African American scientists compared to 29% of white scientists³, this plan was supposed to help motivate people to contribute to the perpetually advancing understanding of genomes. As stated by the National Human Genome Research Institute, the plan would lead to more accurate diagnoses, new drug

¹ "All About The Human Genome Project (HGP)." 2003. 13 Dec. 2013
<<http://www.genome.gov/10001772>>

² Andre, Claire, and Manuel Velasquez. "Read My Genes: Genetic Screening in the Workplace." *Issues in Ethics* 4.2 (1991): 10-13.

³ "NIH Bias Challenged | The Scientist Magazine®." 2013. 2 Jan. 2014 <<http://www.the-scientist.com/?articles.view/articleNo/34236/title/NIH-Bias-Challenged/>>

targets, and the development of practical treatments for many of those, who today, lack therapeutic options.

There are 5 common research domains that help to specify how the human genome is organized: understanding the structure of genomes, understanding the biology of genomes, understanding the biology of disease, advancing the science of medicine, and improving the effectiveness of healthcare. "Researchers around the world are working towards a future when health care providers will use information about our individual genomes to better diagnose and treat disease. While significant challenges remain to our understanding of how the genome operates in health and disease, there are enough examples to say with confidence that genomics research will lead to important advances in medicine," states Eric Green, M.D., Ph.D., and National Human Genome Research Institute director⁴.

The National Institutes of Health News reports that the new DNA sequencing technologies have been largely accepted in the past several years and have been a preeminent reason that genomic research has developed. "It took all the sequencing capacity in the world about 13 years to produce the first human genome sequence. In 2003, around the time the Human Genome Project was completed, technology had improved to the point where 100 machines could sequence a human-sized genome in about three months. In 2011, one machine can produce a human-sized sequence in about five days." said Mark Guyer, Ph.D., director of the National Human Genome Research Institute Division of Extramural Research⁵. Health care providers will have to be educated to have the ability to read and interpret genomic information, and patients will have to get familiar with the information in order to become aware of their own personal risks, participate in clinical decisions, make use of new therapeutic treatments, and alter their behaviors or habits to prevent certain diseases that the genome information informed them of.

Of course, there are implications that result from genetic mapping. According to the American Journal of Human Genetics, which covers many aspects of genetic research and the use of genetics in medicine, it affects people from the psychosocial stance negatively, if the results were negative it could give the individual anxiety and change their self-image⁶. It could also impact their decisions relating to reproduction, education, career, insurance and lifestyle. From the ethical or moral perspective, you might suspect that Christians would oppose genetic mapping. But, a study⁷ done by Chanita Hughes Halbert, Ph.D., whose central focus points were the psychosocial and behavioral outcomes of genetic mapping, found that when it comes to

⁴ "Charting a course for genomic medicine from base pairs to bedside ..." 2011. 17 Dec. 2013 <<http://www.genome.gov/27543215>>

⁵ "Charting a course for genomic medicine from base pairs to bedside ..." 2011. 17 Dec. 2013 <<http://www.genome.gov/27543215>>

⁶ "Points to Consider: Ethical, Legal, and Psychosocial Implications of ..." 2009. 15 Dec. 2013 <<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1801355/>>

⁷ "Spirituality and Religion in Medicine - Educational Module - Genetic ..." 2009. 16 Dec. 2013 <<http://webcampus.drexelmed.edu/religion/module/genetics/perspectives.asp>>

African American women making the decision to get genetically mapped, more women who were faithful and worked together with God in difficult situations were more likely to accept genetic testing. There are still many Christians who would disapprove of genetic testing due to the fact that they believe it is going against God⁸. Things like spirituality, communalism (strong devotion to the interests of one's own minority or ethnic group rather than those of society as a whole), and gender influence a person's beliefs about genetic testing. Overall, though, the decision to accept genetic mapping is mainly based on the individual's cultural beliefs and personal values.

Danielle Simmons, who has a Ph.D. in biological sciences and focuses mainly on the reproduction factor of genetic testing, states that another problem that has come up is the fact that parents might use prenatal screenings as a way to attain their definition of a "perfect child" and may choose to go through with an abortion if their child does not fit their standards. They also might choose to terminate a pregnancy if they find out that their child would be born with a genetic defect through genetic mapping. Not only is this frowned upon by Christians, but this also is controversial among people who are pro-life. The topic of prenatal screenings also dredges up the issue of "designer babies," in which people use genetic testing results and manipulate them to create their "perfect child." This is done by the pre implantation of embryos in an attempt to control the traits that the baby would receive. When "designing" a baby, you can influence the child's hair and eye color, muscles, height, and intelligence. This issue has recently been labeled "gene doping"⁹. This is referring to how athletes have been known to use steroids or hormones to enhance their athletic performance, and parents now have the choice to genetically modify their child to make him or her a better athlete. Because of the fact that "gene doping" increases the amount of proteins and hormones that cells normally make, it would be difficult to detect these genetic performance enhancers. Another reason that genetic modification is used is when parents choose to have another child in order to help another child survive, an instance is when the other child has cancer. The designer baby would be a match for the other child for things such as bone marrow or organ transplants. The baby's sole purpose in life would be to donate and help the other child survive. An example of this is in the book and movie *My Sister's Keeper* which is based on the real life story of two sisters. One sister was a 16 year-old girl with leukemia whose parents made the decision to create or "design" a child in order to help her survive. This may give the child with the illness a greater chance of survival, but it is unfair for the child who must be poked and prodded without a say in the matter. Also, many people believe that genetic engineering is going against God and His creations¹⁰. According to the U.S. National Library of Medicine (the world's largest medical library) and National Institutes of Health,

⁸ "A Christian Perspective on Genetics - The Christian Institute." 2009. 10 Jan. 2014

<<http://www.christian.org.uk/wp-content/downloads/a-christian-perspective-on-genetics.html>>

⁹ Simmons, D. "Genes and Identity: Human Genetic Engineering | Learn Science at ..." 2008.

<<http://www.nature.com/scitable/topicpage/genetic-inequality-human-genetic-engineering-768>>

¹⁰ Christenson, S. "The Ethical Considerations of Genetic Screening." 2009.

<<http://www.ndsu.edu/pubweb/~mcclean/plsc431/students98/christenson.htm>>

genetic testing on children has been controversial¹¹. Because of the fact that children are not competent or able to give consent, they should only be tested if, when the parents and physician weigh the benefits and harms, the child will benefit from the testing.

There are legal implications that come with genetic mapping as well. The New England Journal of Medicine, one of the most prestigious and oldest continuously published medical journal, said that one implication is the issue of employers screening an individual for certain traits before the person is hired. This is called genetic-based elimination; this is viewed as discrimination. This would provide employers with information that could tell them if a person has the personality traits that the company is looking for and even more specific medical information. The Equal Employment Opportunity Commission recently awarded damages to Terri Sergeant, who was fired from her job as an office manager for an insurance broker because she required extremely expensive medication to treat her at worst mildly symptomatic alpha-antitrypsin deficiency (an inherited disorder that could cause lung disease and liver disease). Being fired solely because of the cost of healthcare is an insufficient reason¹². Another legal argument would be that insurance companies could use genetic testing to see what kind of diseases their clients could have and then charge the individual more money based on that because they would be considered high risk for a disease or just deny them. Another common fear is that genetic information could deny them education and loans. According to the Office of the Privacy Commissioner of Canada, which promotes awareness and understanding of privacy issues by the Canadian public, the U.S. federal government adopted the Genetic Information Nondiscrimination Act in 2008 to prohibit employers from misusing genetic information or using genetic information to make decisions based on that information¹³. Most states have laws regarding this as well. California, for instance, has laws that prohibit genetic discrimination in fields such as housing, education, public accommodation, and mortgage lending.

Although genetic mapping comes with implications, there are many positive arguments for it as well. What many people do not realize is that screening is already happening. When babies are born they are screened for PKU (phenylketonuria) which is a rare metabolic disorder that affects the way the body breaks down protein and can damage the brain and nervous system if it isn't treated. Also, the prenatal screening for Down Syndrome has become very common. If she chooses to do so, when a woman is approximately 15 weeks pregnant, she can get genetically screened to predict the genes that the baby could inherit, and also the sex of the baby about 3 to 4 weeks earlier than normal. These tests could also be very helpful to parents by telling them if they are going to have a mentally handicapped child and help them begin to prepare for that

¹¹ "Points to Consider: Ethical, Legal, and Psychosocial Implications of ..." 2009. 15 Dec. 2013
<<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1801355/>>

¹² Guttmacher, Alan E, Francis S Collins, and Ellen Wright Clayton. "Ethical, legal, and social implications of genomic medicine." *New England Journal of Medicine* 349.6 (2003): 562-569.

¹³ "Genetic Information, the Life and Health Insurance Industry and the ..." 2013. 16 Dec. 2013
<http://www.priv.gc.ca/information/research-recherche/2012/gj_intro_e.asp>

child, this could include testing for Down Syndrome or autism. Those who do support genetic mapping argue that it would benefit employees, employers, and society as a whole. According to one study, which focuses mainly on the benefits of genetic mapping in the workplace, 390,000 workers contract disabling occupational diseases (a disease or disability resulting from conditions of employment, such as a disease caused by ammonia) each year and 100,000 of those workers die¹⁴. With the information that genetic testing provides, workers could steer clear of work environments that could potentially be hazardous to their health and therefore prevent certain disabling diseases. An example of this is if a person has the sickle cell trait, their risk for sickle cell anemia may be increased if they are exposed to carbon monoxide or cyanide¹⁵. Genetic screening could also allow doctors to prescribe early treatment and prevent the illness the patient is at risk for. If a person got tested and it showed that they would possibly be inheriting a breast cancer gene, the patient could make the decision to undergo a mastectomy. An example of this is Angelina Jolie, a famous actress, who got genetically tested and discovered that she would likely inherit a breast cancer gene and chose to undergo a double mastectomy. The National Society of Genetic Counselors, who are biased towards genetic mapping, suggested that there was an immediate "Jolie Effect" meaning that many women were inspired by her and chose to get genetically tested. After she revealed her story publicly, the visits to the National Society of Genetic Counselors "Find a Genetic Counselor" website increased by 86%¹⁶. A person could also prevent an illness by opting to adjust the way they live their life, such as eating a certain way to control or prevent diabetes. Obviously if a person was going to inherit an illness such as Alzheimer's, which isn't curable, they might not want to know about it. According to the International Journal of Health Geographics¹⁷, Figure 7, Alzheimer's and dementia is thought to have contributed 400,000 deaths globally in 2002. But, according to the official medication website of Namenda XR, there are currently two types of prescription medications¹⁸ for Alzheimer's that treat the symptoms of the disease, one is an acetylcholinesterase inhibitor, which slows the breakdown of a chemical in the brain called acetylcholine, an example is in the medication Exelon. The other type is Namenda XR, this helps to regulate the abnormal activity of glutamate (a chemical in the brain important for learning and memory) in the brain, these types of treatments came from the website of Namenda XR.

¹⁴ Andre, Claire, and Manuel Velasquez. "Read My Genes: Genetic Screening in the Workplace." *Issues in Ethics* 4.2 (1991): 10-13.

¹⁵ Andre, Claire, and Manuel Velasquez. "Read My Genes: Genetic Screening in the Workplace." *Issues in Ethics* 4.2 (1991): 10-13.

¹⁶ "Angelina Jolie's Doctor Says Her Story Raises Awareness, Saves ..." 2013. 17 Dec. 2013 <<http://abcnews.go.com/Health/angelina-jolies-doctor-story-raises-awareness-saves-lives/story?id=20567547>>

¹⁷ Barford, A. "IJHG | Full text | The shape of global causes of death." 2007. <<http://www.ij-healthgeographics.com/content/6/1/48>>

¹⁸ "What Treatment Options Are Available? | NAMENDA XR ..." 2013. 17 Dec. 2013 <<http://www.namendaxr.com/treatment-options.aspx>>

In conclusion, although genetic mapping is accompanied by many positive results, such as being able to prevent an illness, and essentially save lives, it also comes with implications. There will likely always be questioning of the ethics in genetic mapping and genetic research in general. In addition, if these implications are not controlled, it could cause conflicts for consumers such as between them and their insurance companies or employers. Genetic information should only be viewed by, and kept between, doctors and their patients, and only used by patients to help better themselves. While weighing the benefits and the harms of genetic mapping, I found that the benefits greatly outweigh the harms. Genetic mapping can help a person prevent, control, and prepare for diseases, and consequently save lives.

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