

Sample Essay

INDIVIDUAL RESEARCHED-BASED ESSAY

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Ethical and Legal Implications of Genetic Mapping

(1) For some time, doctors have known that family history plays a role in the development of illnesses, but they didn't believe anything else could be done to improve a patient's health status. Now, when a person is concerned about inheriting certain illnesses that may run in the family, his or her DNA 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. In another words, this confirms how likely an individual is to contract a certain illness. In these situations, genetic mapping can help a person prepare for or even prevent a disease altogether. Yet with all the medical benefits genomic mapping brings, there are many ethical and legal consequences to consider as well. In Fleckenstein's article, "How Maps Lie," she notes that data can be manipulated to "reflect the desires of their creators," which inspires us to consider how we manipulate the world around us to fit our needs and desires. In the field of medicine, the genetic mapping of DNA specifically raises controversy in this regard: what if we can manipulate our genes to fit our own desires? Increasing concerns over whether or not this emerging innovation is a help or a hindrance begs the question: What are the ethical and legal implications of genetic mapping and to what extent do they outweigh its medical benefits?

(2) Initiated by the National Institutes of Health (NIH) and the Department of Energy in 1990, the Human Genome Project launched as an

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international research effort whose aim was to determine the DNA sequence of the human genome, or the entirety of an organism's hereditary information ("All About the Human Genome"). Completed in 2003 in the United States, it gave us the ability to read nature's complete genetic blueprint for building a human being. The project took 15 years to complete and received \$3 billion in Federal funding (Andre and Valesquez).

(3) 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. Though he may have his own biases as the National Human Genome Research Institute Director, Dr. Eric Green, M.D., thoughtfully notes the medical potential of pursuing these domains of research: "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." In essence, the Institute's plan would lead to more accurate diagnoses, new drug targets, and the development of practical treatments for many of those, who today, lack therapeutic options ("Charting a Course").

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(4) The National Institutes of Health reports that the new DNA sequencing technologies have been well-received in the past several years and have been a preeminent reason that genomic research has developed so rapidly (“Charting a Course”). But with this rapidly spreading acceptance come hurdles that have yet to be addressed. Health care providers, for instance, will have to learn how to read and interpret genomic information, and patients will have also have to become familiar with the information in order to better understand their own personal risks, participate in clinical decisions, make use of new therapeutic treatments, and alter behavior or habits in response to the genome information they receive.

(5) Of course, there are other medical 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 negatively affects people psychosocially; in another words, if the results are negative it may give the individual anxiety or alter his or her self-image (“Points to Consider”). It could also impact the person’s decisions relating to reproduction, education, career, insurance and lifestyle. Meanwhile, from a personal, moral perspective, we might suspect that the Christian community might oppose genetic mapping because of the clash between scientific research and religious belief. But a study conducted by Chanita Hughes Halbert, Ph.D., which targeted the psychosocial and behavioral outcomes of genetic mapping, found that

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African American women who were faithful and worked together with God in difficult situations were more likely to accept genetic testing than those who did not have an established faith (“Spirituality and Religion in Medicine”). While the results of this study were compelling, it still remains that there are still many Christians who disapprove of genetic testing because it “goes against God and His creations” (Christenson). Beyond spirituality, other social or cultural considerations that influence a person’s beliefs about the ethical value of genetic mapping, including factors like communalism (strong devotion to the interests of one’s own minority or ethnic group rather than those of society as a whole) and gender. These varying points of view seem to indicate that the decision to accept genetic mapping is largely dependent upon one’s moral and personal values.

(6) Dr. Danielle Simmons, whose studies in biological science focus mainly on the impact of genetic testing on reproduction, states that another major ethical problem that has come up is the fact that parents might abuse prenatal screenings as a means to attain the “perfect child.” They may choose, for instance, to terminate the pregnancy if genetic mapping were to reveal that the child may be born with a genetic defect such as Fragile X. Not only is this frowned upon by the religious community, but it may also prove controversial among those who deem themselves advocates of ‘pro-life.’ The ability to prenatally screen a fetus further dredges up the issue of “designer babies,” where parents use genetic testing results and manipulate the DNA of their unborn child. This process is carried out through the pre-implantation of embryos in an attempt to control the traits that the

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baby would receive. When “designing” a baby, one can influence a child’s hair and eye color, muscles, height, even intelligence. Because of the ability to manipulate the baby’s muscles in particular, this capability has recently been labeled, “gene doping,” a reference to those athletes who have been known to use steroids or hormones to enhance their athletic performance. Because “gene doping” increases the amount of proteins and hormones that cells normally make, it would be difficult to detect these genetic performance enhancers, thus raising major ethical concerns in the field as a result.

(7) Another, perhaps more honorable reason parents might pursue genetic modification would be to help a family member currently suffering from an incurable disease such as cancer. This process would help this child survive because the ‘designer baby’ would intentionally be matched to aid the sick child in procedures such as bone marrow or organ transplants. Though this may give the child with the illness a greater chance of survival, it is unfair and perhaps unethical altogether for the other child who must be poked and prodded without a say in the matter. In fact, according to the U.S. National Library of Medicine—the world’s largest medical library—and the NIH, genetic testing on children is controversial primarily because children are not competent enough or capable of giving their own consent (“Points to Consider”). If this is to be the way of the future, these children should only be tested if and only if the child will benefit in some way from the testing.

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(8) Despite the negative implications, there are many positive arguments for genetic mapping as well. What many people do not realize is that screening is already happening. When babies are born they are screened for PKU, or 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, a pregnant woman may elect to get genetically screened to predict the genes the baby could inherit. Ethically speaking, these tests could be very helpful to parents by preparing them in advance for the challenges that may lie ahead if their child possesses the traits of Down Syndrome or Autism. In cases like this, it would serve the parent well to become educated in these exceptionalities before the baby is born and to build a support system for once the baby arrives.

(9) Just as genetic mapping has mixed reviews ethically, it also contains a number of legal implications worth considering. The New England Journal of Medicine, one of the most prestigious and oldest continuously published medical journals, indicates that one of these implications involves the ability of employers to screen an individual for certain traits as a basis for hiring. Also called 'genetic-based elimination,' this process could be viewed as a modern form of discrimination. Specifically, it would provide employers with information that could reveal whether a person has certain personality traits valued by the

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company (Guttenmacher et al.). Despite this fine line that calls genetic mapping into question, there are steps being made to avoid it. The Equal Employment Opportunity Commission recently awarded damages to Terri Sergeant, for instance, who was fired from her job as an office manager for an insurance broker because she required extremely expensive medication to treat her mildly symptomatic alpha-antitrypsin deficiency—an inherited disorder that could cause lung disease and liver disease (Christenson). In this case, being fired solely because of the cost of health is wrong.

(10) Another legal issue that surfaces regards the use of genetic testing to unfairly hike insurance premiums. Insurance companies could use genetic testing to see what kinds of diseases their clients may have, then charge the individual more money based on these findings because they would be considered ‘high risk’ (Andre and Valasquez). A final common fear that poses legal concern involves the possibility that genetic information could deny a person academic loans or an education altogether. To avoid any of these kinds of problems, however, 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 information (“Genetic Information”). Most individual 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 (“Points to Consider”).

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(11) Moreover, 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 die (Andre and Valasquez). With the information that genetic testing provides, though, workers could steer clear of work environments that could potentially be hazardous to their health and therefore prevent certain disabling diseases. This applies particularly well to a person who has the sickle cell trait; their risk for sickle cell anemia may be increased if they are exposed to carbon monoxide or cyanide (Andre and Valasquez). Without knowledge of their predisposition, they may expose themselves to these chemicals in the work environment, thus triggering the disease.

(12) Meanwhile, one of the greatest medical benefits of genetic screening is that it would allow doctors to prescribe early treatment and prevent the illness of at-risk patients. If a patient's test results showed that he or she could potentially inherit a cancer gene, for example, the patient could make the decision to undergo preventative surgery. An example of this is Angelina Jolie, a famous actress whose test results prompted her to undergo a mastectomy to avoid breast cancer. The National Society of Genetic Counselors, though they are vested in

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interest, took issue with this however, suggesting that the “Jolie Effect” thereafter pushed women to seek genetic counseling, which even led some into potentially unnecessary surgeries whereas other alternative steps could have been pursued instead (“Angelina Jolie’s Doctor Says”); as an example, merely altering lifestyle choices including diet could help to avoid a genetic predisposition to diabetes.

(13) In conclusion, although genetic mapping is accompanied by many positive results, such as preventing an illness, it also comes with implications. If these implications are not controlled, it could cause conflicts for consumers such as between them and their insurance companies or employers. There will likely always be questioning of the ethics in genetic mapping and genetic research in general. 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, it appears that the benefits greatly outweigh the harms since it can help a person prevent, control, and prepare for diseases, and consequently save lives.

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