Bioethics and health information management philosophy essay

Philosophy

The Human Genome Project has been frequently compared to both the Manhattan Project and the Apollo Project. Consequently, the HGP teaches us volumes about science and the unforeseen impact of technological " advance." As these advances come to fruition, the Health Information Management Specialists will perhaps face a host of many challenges of which they were never presented before in their field. The magnitude of such advances will continue to push the limits of information management and integration systems. These specialist will meet head-on with legal and ethical challenges, while having to come to terms and identify with their virtue ethics, moral sensitivity; courage, judgment and motivation for the best interests of the stakeholders. Chiefly the implications and obligations of the HIM specialists are elevated. Genomics is the development and application of cutting-edge biological investigation and methods of genome-scale technologies. As Genomics evolves, so will bioethics, while addressing the fundamentals of ethics, legal and social Implications. Through a process known as genotyping, which identifies the variations linked to certain traits, diseases, drug sensitivities and total genetic make-up, individuals will learn that genomics betrays little about how personal their journey will be. Some may learn of comforting assurance, while others may learn troubling things to these allusions to the past. Many will learn of their medical destiny and longevity through predispositions of diseases and inherited disorders, while others may unlock the mysteries of their ancestry and learn that their ancestors aren't who they thought they were, that their father isn't their real father, some fathers may learn that their little girl will have breast cancer through these tests. Humankind is experiencing a bourgeoning medical

revolution; a genome sequencing revolution of which will affect the entire civilization of planet earth; a technology that the medical environment has never seen the like of. This technology may very well not only transform the way we understand ourselves, however It's a technology that could not only change how we understand ourselves, though moreover how we receive medical treatment in the future. Soon, people across the globe may have access to their own complete personal genome project. The Human Genome Project was developed to detail genetic and physical map of the human genome that began as a coordinated effort between the U. S. Department of Energy (DOE) and the National Institutes of Health (NIH) during the Regan era. In addition to identifying all the human genes; scientists would determine the sequences of all the base pairs in the human DNA; store the information in a database; develop tools for analyzing data; and address the ethical, legal, and social issues that would arise from the project (Collins et al, 1998). As the project came to its completion, scientists were challenged with the considerations of a whether they now have a Treasure Trove or Pandora’s Box with a tiger jumping out, as their advances in genetics herald astonishing possibilities for humankinds , health and medical care, and scientific research, social and individual implications, ethical dilemmas and a host of additional possibilities. These issues are rather perplexing yet troubling. And they won’t wait. The Human Genome Project was finally completed ten – years ago with the promises of personalized medicine. Today that has not happened fully, partially because a physicians cannot provide personalized health care for their patients until the physician knows exactly what condition or disease their patient may have while also part of

the bigger questions are knowing the sequences of the patients and what variations they've inherited. So you want your own genome sequence and want to learn about your genetic tendencies, quirks and precursors? Should you, would you, change your life if you knew about those genetic quirks and precursors? For $500. 00 USD a person can learn much about themselves. Using the genetic knowledge to guide our health care is a fantastic leap in patient care. However there are many sectors of the society that are left out of this process. Chiefly, the genome sequence is already mapped out. However, the connection between genome sequencing and the associations of different ethnic and racial groups have fallen off the charts. That being said, generally associations' studies consist of a few thousand individuals, of which are Caucasian people. In other words, if you're a person who is Japanese American, African American, or a Native Indian, well, there really is not any great associations between the two, so that limits who society will benefit and who won't. The other challenge is that while the genome sequencing is mapped out and the associations are in further studies, there still remains a host of unknown variations and associations. Though there are genes that we can identify that are responsible for some diseases and conditions, such as a family history of breast cancer or prostate cancer, these persons have a greater chance for being a candidate for genetic testing. This is only because the studies and associations have been targeted. Whereas, a person with heart disease in the African American community will most assuredly die of this number one killer amongst the African Community. The box or throve, what every flavor you choose, has already is already opened. The psychological impact on our society is

immense and should be studied in greater numbers. Until then our society and health care community will have to adjust our ethical thought process. So what is the impact of our knowledge? With that said, knowing that there's breast cancer history in a family, then having this genomic testing, finding out you do have the gene. What is the impact of that knowledge? Humans should not be testing individuals without proper counseling. Physicians, social workers, psychologists and HIM specialists are not really equipped as of now to deal with such risk factors. As an illustration, Caplan, 2011, argues that a man comes in to his office who wanted to test his 13-year-old daughter because there was a lot of breast cancer in his family. And we said to him, " well, you can test your 13-year-old daughter, although maybe it would be better to wait until she becomes an adult and decides whether she wants to know or not herself. We don't have much to offer now." And the man said, " look, if that 13-year-old daughter of mine tests positive, I'm going to have her breast buds removed because I don't want her to face what other people in my family -- other women in my family have gone through."" Well, that just startled us. We had never thought of someone prophylactically preventing breast development in someone who might be at risk for breast cancer. So the emotional stakes if someone says, you are highly at risk for Alzheimer's or Huntington's disease, are huge and I think right now it's irresponsible for anyone to be doing testing without counseling." This is an amazing story from Dr. Caplan, though I’m sure this man had somewhat admirable intentions, a father making such consent decisions for his little one is rather difficult to comprehend. What affects do this man’s actions have on this little girl, for that matter the physicians

actions? If what the father says is true, these actions may very well save the little ones life, nonetheless, if possible this child could wait until she was a young woman at the age of eighteen or twenty-one to decide with informed consent. Testing for children should not afforded to neither the children nor their parents unless there is some sort of therapeutic options in place. Consequently, if a patient gets tested and receives their genetic sequences and associations confirming that they are at risk a disease, then this also confirms that this patients biological relative may too be at risk. The question comes in to play as to if the patient knows a precursor to a diseases, does that patient need to fully disclose this information to their biological relatives? According to Watson, who was sequenced in 2007, he specifically asked not to be told the identity of which variant of that gene he had inherited because he didn't want that bit of too much information. Even though he was nearly 19 years old, whether that was a disease that he might -- he might have to worry about in his final years. On the other hand, there are people who would want to know information about themselves just because it's their informationAs we discussed earlier, a person can obtain their generic sequencing for as little as $500. 00. Just spit in a cup or swap your mouth and send off you DNA. But how safe is that person’s genetic information? There again , is not much associations available to the general public. Sure you can get your code, and a little information about your ancestors, some even offer to provide a unique diet to fit a person’s genes. Right now, unless you just want to have copy of your gene, these services still yet remain somewhat scientific beneficial. Assume you go ahead and send off your DNA, who are you sending it to? How is you DNA protected?

What are the risk factors? What happens is one of these third party genetic testing organizations gets bought out by a healthcare company, an insurance company or even the government? Will the insurance companies or employers be able to use this information? There are some stopgaps in place called the Genetic Information Nondiscrimination Act (GINA), which restricts the use of genetic information in writing health insurance. But in terms of employment, disability insurance, life insurance, there are a lot of areas where you still might be penalized if people got a look at your DNA. According to the Genetic Information Nondiscrimination Act (GINA) of 2008, President Bush has signed into law the Genetic Information Nondiscrimination Act (GINA) that will protect Americans against discrimination based on their genetic information when it comes to health insurance and employment. The bill had passed the Senate unanimously and the House by a vote of 414 to 1. The long-awaited measure, which has been debated in Congress for 13 years, will pave the way for people to take full advantage of the promise of personalized medicine without fear of discrimination. While, The Department of Health and Human Services continues to explain the Genetic Information Nondiscrimination Act (GINA) so that investigators and researchers can understand the law and its prohibitions related to discrimination in health coverage and employment based on genetic information.

Inasmuch as for years, American hospitals have been testing newborns for over 50 different genetic diseases known as the neonatal heel prick or the Guthrie heel stick test. The state of Texas has been tracking the blood samples of newborns for over forty-years to monitor genetic diseases in babies. Though anonymous as theses samplings were, when it was leaked out that the Texan government saved these said samples without implied consent, the government was forced to destroy the works of many decades.

Lack of consent by future generationsLappé , 1991, argues that some philosophers, ethicists and analysts disagree that it is wrong in principle to change the genetic makeup of future individuals through genetic sequencing germ line interventions because we cannot obtain their consent. There still remains an obligation and most importantly a responsibility to guard the interests of future descendants who are currently voiceless in this respect, somewhat in respect also to the Baptists moral cry for the unheard fetus. If we do have responsibilities to our descendants, our obligations certainly include determinations eliminating toxic genes and thereby improving the health and making life better of future generations for our children and successive descendants. The healthcare sector needs to be careful with the information that they are entrusted to safeguard. If HIM specialists aren't careful about getting informed consent and when physicians don’t understand the genetic information and can't really give a patient a good informed consent, it's trouble because the public will quickly be suspicious that there's more harm than good here. HIM specialists need also to study more law, including adoption laws. Adoption laws and closed records have been part of the American society for decades. However, parents rather

want-to-be- parents may actually request the genetic makeup of their prospective child. This brings about another item we discussed previously, implied consent from the voiceless. This form of genetic testing will assuredly leave behind thousands of children of whom would be other adopted out, as prospective parents for these children would opt for the " perfect child." The perfect child will be discussed later text. What are the broad legal ramifications for the HIM specialists when confronted with adoption law and closed records are yet to been approached. With the emergence genetic testing, a trained individual would know that same genes lined up for long stretches of chromosomes is that of incest. This indicates some past of interbreeding, either that the person may be aware of in their past because of rape or assault or maybe that they didn't know because they wound up being the product of a marriage between people who were, let's say, by a crazy chance, children from the same sperm donor. The later, the sperm donor, and for that matter egg donor, with the advent of genetic knowledge and the end of closed records, this secrecy will end. Humans will feel entitled to this information if they are to plan a road map to ah realty life. This information will be a need to know information as their genetic parents are their key to their genetic analyses. However on the other hand, the donors will want to assure that their privacy is also protected. How will the HIM specialist deal with these challenges? Perhaps, the advent of this genome knowledge’s will collapse the adoption process. Does the donor have any protected rights to their personal genetic material? Can these materials be used without the donors consent to further patented genetics? Actually, according to the Federal Supreme Court Chief Justice Robert E.

Davis, " once your tissue or DNA leaves your body, you really have no property rights to it. And the courts have consistently said, if we start cutting patients and donors in on the action financially, then this is going to hurt the fragile biotech industry. " Soon people will want their embryos or their gametes tested, by using that information to design their perfect descendantsThis leads me to eugenics, of which many Americans fell that only Hitler and Mussolini embraced, however America was several years ahead of these two by introducing eugenics that was enacted in Indians, USA in 1907, well ahead of the WWII atrocities. According to Procto, 1936 other countries that wanted the perfect baby were; Denmark (1929); Norway (1934); Sweden (1935); Finland (1935?) While these countries were consideration such selection only up until the end of WWII; Hungary; United Kingdom; Switzerland; Poland; Japan; Latvia; Lithuania" Wir stehen nicht allein: " We do not stand alone". Nazi propaganda poster from 1936. The woman is holding a baby and the man is holding a shield inscribed with the title of Nazi Germany's 1933 Law for the Prevention of Hereditarily Diseased Offspring (their compulsory sterilization law). The couple is in front of a map of Germany, surrounded by the flags of nations which had enacted (to the left) or were considering (bottom and to the right) similar legislation." It is important the we make the distinction between of genetic therapy and genetic enhancement, as, one of the biggest challenges we face today still remain the same as it did century ago; eugenics, meaning, meaning " good birth," became a movement in the early part of the 20th century with the goal of weeding out what proponents believed were the " bad" traits of society and promoting " good" ones. Negative eugenics sought to discourage

breeding among those considered to be socially inferior, including the so-called feeble minded, criminals, and the incurablyDyck, 1997, argues Nazism, which went well beyond these measures by officially sanctioning both compulsory sterilization of patients and the killing of members of " inferior" races, is the most horrendous example of eugenics as a state policy. The aforementioned is seemingly close to the genetic sequencing associations. We will also see another problem in the education of physicians together with HIM specialists, as most physicians today in America went to medical school ten to thirty years ago and they know virtually nothing about the next generation of physicians, let alone what genome entails . medical schools will have to relearn ho to teach and learn. The technology is so fast that the problem -- the bottleneck now is increasingly how do you turn 6 billion letters of DNA into a sort of a red light, green light decision that a family physician can provide some meaningful guidance to their patient and how is that than communicated, how does the doctor fully integrate that information (unintelligible). The religious traditions vary quite considerably in their views on the status of human genome sequencing and on the question of whether an embryo is to be regarded as a fully human person from the moment of conception, of which has been highly debated among the world. While they share a deep uneasiness regarding actions that might alter human nature or affect human relationships, the National Council of Churches, 1986, position of religious bodies on the appropriateness of genetic interventions have ranged from the studied to the well-known intentional silence on the matter. Like many other technologies, our ability to foresee the full consequences of going forward with human genome

sequencing will be partial at best. Subsequently, for this reason there is a host of concerns among religious thinkers that our eagerness for this technology and its benefits will tend to downplay the limits of our ability to know the effects of our acts and to proceed responsibly. Conclusion

Balancing Scientific Freedom and Responsibility

People recognize the enormous power of expert knowledge andthe influence it can have on their lives. All of us look to scientistsand physicians for authoritative answers to complex and seriousproblems of the day. And as a society, we have quite readily investedin the education and training of scientists, in research on importanthealth and social issues, and in the infrastructure essential forsustaining scientific research. Nevertheless, recent history is repletewith examples of increasing apprehension on the part of Americansabout the effects of science, especially in the biomedical arena, ontheir lives. As a result, the extent of social controls over science hasgrown during the past several decades, as society tries to balance itsfaith in free scientific inquiry with broader social va lues. Research by Guston (2000) supports thatWORKING NOTESInequities in access to genetic therapies