Honors Summer 2014 Thesis:

Public perceptions of genetic testing

Hà Vũ Tiên Dung

Simon Fraser University

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Abstract

There are many risks and concerns accompanied with the benefits of big data in genomics science. In a recent poll conducted by the Huntington Post and YouGov organization on the DNA breakthroughs, the majority of Americans (38%) is excited about the main scientific breakthroughs on human, plant and animal DNA (YouGov, 2014). However, many of them are concerned about the privacy and ethics of genetic research. 34% of the surveyors strongly disapproved of scientists using DNA and cloning technology to bring woolly mammoths and other extinct species back to life (YouGov, 2014). 52% strongly disapproved of scientists using research on human DNA to produce children with unusually high intelligence or other special attributes (YouGov, 2014). Lastly, 35-37% of American surveyors are very worried about that scientists may begin to 'play God' (YouGov, 2014). What can these statistics tell us? Apparently, they point out to us that there is a clear distrust between the public and the experts (the scientists). Also, there is a high level of risk perception on genetic/genomic technology among the public. Bioscientists, social scientists, policymakers and other experts in the field are working hard to bringing genomics technology from the lab setting into the real healthcare system; however, they seem to miss or ignore the public's desires and opinions in this issue. Therefore, this paper will review the genomics literature and the impacts of genetic testing among the public, and conduct a survey among Simon Fraser University students as a sample representing the populations of British Columbia to explore the public perceptions on multiple themes of the knowledge and attitude of the public towards genetic testing and government legislation regulating; the impact of genetic technologies on women; the health system implications; the privacy concerns over genetic information including access, control and trust; and the ethical implications of genetic testing

This is the century of genomics. From the human embryo to the food we eat every day, they can all be modified by genetic technology. In fact, DNA technology is blossoming and changing the world today. In 2003, the success of Human Genome Project (HGP) allowed scientists to sequence the whole human genome. This achievement has led to many promising breakthroughs in science and medicine. Through whole genome sequencing, researchers can tailor treatments and produce personalized medicine for diseases such as cancer, Huntington's diseases and so on. Also, with the advancement of DNA technology, the cost of sequencing the human genome has been dropping sharply. Today, for $99, we can easily purchase a genetic test through 23andMe, a well-known American direct-to-consumer genetic testing service. All of these medical achievements are contributed with the help of big data. Big data enables the collection and storage of hundreds of petabytes of human genomic data, which allows our human genome to be sequenced faster and cheaper (Vanacek, 2012). Therefore, this is also the era of big data.

In 1994, Time magazine's cover featured a story entitled "Genetics: The Future is Now" (Caulfield, 2012, p. 100). A decade later, Time again ran another cover on genetics to tell us that "gene science has changed our lives" (Caulfield, 2012, p. 100). Then, two decades later, in 2013, Time featured a story called the "Angelina Effect"; it depicts the major breakthroughs of genetic technologies in the diagnostics for high risk genes and the celebrity impact on public perceptions of biotechnology. In a very recent study conducted by PewResearch, most Americans (59 percent) are very optimistic about the positive impacts of technology and science on society (Smith, 2014). At the same time, 30 percent of Americans think these changes in science and technology will lead to a worse future for human beings (Smith, 2014). In fact, science is a double-edge knife. In the case of genetic technologies, there are benefits and challenges. The goal of my paper is to explore public perceptions of genetic testing in British Colombia. This

includes the knowledge and attitude of the public towards genetic testing; the impact of genetic technologies on women; the health system implications; the privacy concerns over genetic information including access, control and trust; and the ethical implications of using genetic informationto contribute to the policymaking process of bringing genomics technology from the lab setting into the healthcare system.

The century of biotechnology

Today, the cost of whole genome sequencing has dropped to thousands of dollars, and soon it will be a few hundred, the equivalent of a flight ticket from Vancouver to San Francisco. The genetic testing market is blossoming more than ever with the boom of biotechnology stocks in the past two years (Herper, 2014). The biotech boom has been fueled mostly by innovations in therapeutics, the creation of new lucrative drugs and the research breakthroughs in life sciences (Herper, 2014). With the decreasing cost of genetic testing and the development of biotechnologies, the public now has easier access to the structure of their genes and detecting the the risk their genetic diseases. However, does the public fully understand what genetics is? That is one of the questions that this paper is trying to answer.

Genes are the units of heredity. This was first illuminated in the 1860s by Gregor Mendel, who tried to understand what causes the traits in pea plants, such as wrinkly pea skin, passing from one generation to another (Caulfield, 2012, p. 103). It was not until 1953 that the structure of the unit of heredity for Deoxyribose Nucleic Acid (DNA) was published in a one-page article in the journal *Nature* by American biologist James Watson and English physicist Francis Crick (Caulfield, 2012, p. 103). The discovery by Watson and Crick led to a variety of new technologies that allowed scientists to read the biological code of human DNA (Caulfield, 2012,

p. 103). This ability to analyze human DNA brought higher ambitions in bioscience to sequence the whole human genome. The sequence of human genome is the study of a 3-billion base pair consensus sequence of the euchromatic portion generated by the whole-genome shotgun sequencing method (Venter, 2001, p. 1305). By decoding our human genome, we can understand the differences in DNA mutations resulting in complex diseases (Chow-White, 2008, p. 1175).

The two well-known projects that study the human genome are: The Human Genome Project (HGP) and the Human Haplotype Map (HapMap). In 1990, the HGP was launched in the United States with the funding of three billion dollars. It took nearly a decade and a whole team of experts around the world to finish it in 2003. In 2003, 99 percent of gene-containing part of human DNA sequence was sequenced with 99.99 percent accuracy (Caulfield, 2012, p. 104). The significance of this project is immeasurable. As stated by the director of the National Institutes of Health, the goal of the HGP is to improve human health and reduce the burden of disease for all people (Caulfield, 2012, p. 104). The second project applies a different method to study our DNA. The HapMap project studies our genomes at different population groups of European descent, the Yoruba population of African origin, Han Chinese group from Beijing, and Japanese people from Tokyo (Bush and Moore, 2012). The purpose of the HapMap project is to understand the variation in genomics across different ethnic groups to personalize medicine and treatments for diseases in according to our race (Bush and Moore, 2012).

In 2003, the Human Genome Project, funded by the government, cost $2.7 billion to sequence a human genome (Lohr, 2013). Today, the whole genome sequencing only costs $3000 (Lohr, 2013). It is predicted that in the next three years, that $3000 testing cost will go down to only $100 (Lohr, 2013). In fact, 23andMe, a Californian-based DNA testing service, offers a $99 package for DNA testing to find out our personal genetic information (Murphy, 2013). It is just

amazing how the cost of those scientific testing can plummet in such a short period of time and become openly accessible for the public. That is why most Americans are very excited about breakthroughs in science and technology; however, we should be more critical in measuring the success of the HGP and the use of genetic testing: "To what extent did the scientific and medical advances derived from the HGP reduce the burden of disease for all people?" (Caulfield, 2012, p. 104). Trying to answer this question requires us to understand the significant factor behind the success of the HGP that promises to change everything and to cure all our diseases. That factor is big data.

The era of big data

Big data is the giant tool that controls how we live, work and think (Mayer-Schonberger & Cukier, 2013). At this moment, big data might be a new concept for a majority of people; however, it is constantly reshaping all aspects of our lives. In 2009 when the virus H1N1 actively struck, while the old-school government official statistics failed to report the virus trend, Google's system successfully predicted and identified the spread of the flu (Mayer-Schonberger & Cukier, 2013, p. 2). The success of Google's system in indicating the massive flu trend was built on the technique of "big data". Big data is defined as "the ability of society to harness information in novel ways to produce useful insights or goods and services of significant value" (Mayer-Schonberger & Cukier, 2013, p. 2). For big data, knowing "what" is enough; the "why" is unnecessary to explore and "the more and the messier the data are, the better the measurement is" (Mayer-Schonberger & Cukier, 2013, p. 7). Approximation is good enough, accuracy or precision is not required (Mayer-Schonberger & Cukier, 2013). The core of big data is prediction and its principle is N=all (Mayer-Schonberger & Cukier, 2013). By gathering a tremendous amount of data, big data allows us to identify trends and patterns in all areas of life. We are

living era exploding with data. In contrast to Medieval Europe when a stock of information took fifty years to double after the invention of printing, information and data are exponentially growing every second. Google processes 24 petabytes of data everyday; that amount exceeds thousands of times the quantity of printed materials in the U.S. Library of Congress (Mayer-Schonberger & Cukier, 2013, p. 8). Facebook, which is just less than 10 years old, stores 10 millions new photos uploaded by its users every hour (Mayer-Schonberger & Cukier, 2013, p. 8). Everyday, Twitter exceeds 400 million tweets per day in 2012 (Mayer-Schonberger & Cukier, 2013, p. 8). Thus, in 2013, the amount of stored information around the world is estimated approximately 1,200 exabytes of which more than 98 percent is digital and less than 2 percent is printed (Mayer-Schonberger & Cukier, 2013, p. 9).

In health settings, big data plays a significant role in sharing and storing massive amounts of data about human genomic traits. HGP is an international collaborative project between many expert teams around the world, including the Department of Energy (DOE) and the National Institutes of Health (NIH) in the U.S. as well as the Wellcome Trust at the Sanger Center in Cambridge, England along with other international partners (Collins, 1999). It took sixteen years to upload the first billion bases into the data base; today, with the help of big data, it only took fifteen months to add the second billion bases into a computer data sharing system called GeneBank (Collins, 1999). GeneBank stores over 39,000 species and receives over 200,000 queries a day for information on gene sequences and over 60,000 sequence-comparison searches every single day (Collins, 1999, p. 29). For research purposes, all this data is available to the public domain so that any scientist, whether based at a university, a corporation, or a government lab, can have access to the sequence data (Collins, 1999, p. 29). For Collins (1999), this is a significant advancement in data-sharing for a public-private partnership of genomics research (p.

33). All the genome data is gathered in the cloud, from within a massive universe of information; and through algorithmic queries, scientists seek for patterns and similarities that reveal general insights about whole populations (Miller, 2014). That is how big data works. At the same time, big data can also generate some misperceptions and mischaracterizations about human conditions as well as become a massive form of surveillance on the societal population.

Collins (1999) also clearly stated the four characteristics of the HGP, which are: accurate, assembled, affordable and accessible (p. 29). First, the sequence must be accurate. Secondly, from the short lengths of sequenced DNA, scientists can assemble longer, genomic-scale pieces that reflect the original genomic DNA (Collins, 1999, p. 29). Third and fourth, the new whole genome sequencing technology must also be affordable and accessible to the public (Collins, 1999, p. 29). It seems like the HGP actually fulfilled all those promises. The most outstanding example of the affordable and accessible application of the HGP is the DNA testing kit from 23andMe. For $99 a kit, 23andMe can provide us detailed ancestry information, responsiveness to 25 drug therapies, and the probabilities of having complex diseases embedded in our genes such as BRCA1 mutation which could cause breast cancer in women (Miller, 2014, p. 1). The goal of 23andMe is to revolutionize the healthcare industry by giving the public easy access to their genetic information. A more ambitious goal of 23andMe is to create "the world's largest secure, private database of genotypic and phenotypic information that can be used for comparison analysis and research" (Miller, 2014, p. 3). By fall 2013, 23andMe had analyzed the DNA of 650,000 people, making it the one of the biggest biobanks in the world (Miller, 2014, p.1). 23andMe is well known for their generous funding and collaboration with Michael J. Fox Foundations in the research of finding the cure for Parkinson's disease. However, the dangerous thing about 23andMe constructing their own private biobank is that by providing any sample to

the company, we automatically give them our consents to use our genomic information in any research or commercial products. As a result, we give up the rights to our fundamental privacy and control of our own genetic information. Are we fully aware of all the risks of genetic testing? Trying to answer this question requires us a good understanding about the public perceptions of genetic technologies. The most popular source for the public to seek information about genetic and medical advances is from the media; and thus, it is worthwhile to examine the relationship between biotechnology and the popular media.

Genohype: the selling of science

Genohype is a phenomenon in which the media portrays science, in general, and genetics, in particular, inaccurately and unrealistically. Technically speaking, the term 'media' includes all forms of popular media from newspapers, movies, television news and social media. For example, within the movie industry, there are innumerous movies portraying superheroes or superpower with special genes in this past decade. The Canadian actress, Rachel McAdams, is a perfect example. In less than five years, she starred in two movies, which are *The Time Traveler's Wife* (2009) and *About Time* (2013), playing the wife of a man who has the time travel superpower in his genes, which led to the separation of the married couple. In addition to the fictional portraits of genetics in movies, our genes have also become a source to blame for all the social issues: "Is 'Laziness Gene' to Blame for Couch Potatoes?"; "The Good Gene: Does Our DNA Compel US to Seek a High Power?"; "Always Lost?: It May Be in Your Genes"; "Party Animal: It May Be in Your Genes"; "Marriage Problems? Husband's Genes May Be the Problem"; and "Genes May Affect Popularity, Researchers Say" (Caulfield, 2012, p. 100). With these shocking headlines, the media aims to individualize our social issues as own our problems

embedded in our genes and to shift away our collective responsibilities as a society, and broader sociopolitical factors causing the problems.

However, we might be surprised to know certain studies actually show that the media representation of science is accurate. In a survey of first authors from the scientific community who had interactions with the media, 86 percent of the respondents rated the scientific studies coverage as "accurate" (Caulfield, 2004, p. 337). In addition, among 207 news stories on drugs for disease prevention, most of them show both sides, the benefits and the harms, of the drugs; only 15 percent presented both relative and absolute benefits (Moynihan et al., 2000). As a result, we should not completely blame the media for the inaccurate claims about science. There are always reasons for everything; and the selling of science in the media also has its purposes. Under the increasing pressure to attract more grants or funding, researchers and research institutions tend to expose themselves to the media with the emphasis on the near-future benefits of their findings (Caulfield, 2004, p. 338). Therefore, university research gradually is becoming an important part of the economic agenda and their research is also turning into a commercially driven research environment associated with potentially commercial products (Caulfield, 2004, p. 338). As a result, our three parties: researchers, research institutions and the media all can share short-term benefits as 'complicit collaborators' in the business of selling scientific discoveries.

In some circumstances, academic scientists and researchers are reluctant to collaborate with reporters to sell their credibility. In a study on trust and public perceptions of biotechnology research, university scientists are ranked with high credibility and mostly trusted by 53 percent of Canadians (Caulfield & McGuire, 2012). The more trusting the public are with researchers, the easier for them to buy into the media stories portraying scientific research. Overly optimism or unrealistic view about genetic discoveries can negatively impact public understanding of

biotechnology. For example, in one study about patients' attitudes about autonomy and confidentiality in genetic testing for breast-ovarian cancer susceptibility, researchers found out that 95 percent of women with first-degree relatives of women with breast cancer strongly felt the need to get their genes tested in spite of their physician's recommendation to the contrary (Caulfield, 2004, p. 338). On May 14, 2013, American actress and director Angelina Jolie shared with the world through her personal letter to the New York Times that she had gone through a double mastectomy to prevent her high risk of having breast cancer and ovarian cancer (Jolie, 2013). In the letter, Jolie was hoping to raise awareness for women, who may be living under the shadow of having cancer, to take action and get their gene tested (Jolie, 2013). Jolie's story has inspired as well as raised awareness for many people about the effectiveness and accuracy of life sciences technology and promoted the business of genetic testing or whole genome sequencing for health risk preventions. That is why Time Magazine called it the Angelina Effect.

The power of the Angelina effect can be demonstrated by its popular trend on the social media. The New York Times Twitter post on her story was retweeted almost 5000 times and received almost 2000 comments and a Google search of online news postings yielded more than 2000 results (Hurley, 2013). This data indicates that celebrities have an impact on promoting public health issues. Yet, in a current study on the Angelina effect, the researchers concluded that while three out of four Americans knew about Angelina Jolie's double mastectomy, less than 10 percent of respondents understood fully about the BRCA gene mutation or genomics testing (Borzekowski, 2013). Therefore, celebrities only have the power to raise awareness but not to improve scientific public understanding in health-related issues. A recent study shows that of more than 8000 patients, about 2500 ended up having a procedure to remove their breast. However, the study found that in 49 percent of such cases, the mastectomy was either needless or

was being carried out because of a failed previous operation (Donnelly, 2014). Therefore, there is an obvious evidence that the public does not have good understanding about genetic testing nor sufficient guidance from the healthcare system to make the right decisions with their genetic results. In the next section, we are going to examine genetic literacy in academic setting.

Literature review: an increasing trend in research on genomic technologies

In contrast with the plummeting of the cost for whole genome sequencing, the literature trend in genetics has been rocketing in the past few years. By using PubMed miner, a database storing electronically available publications of biomedical and molecular biology literature, we collected data about different topics on genomics technologies from National Human Genome Research Institute including 'genetic testing', 'medical genomics', and 'genetic discrimination'. These topics focus on a diverse range of disciplines from the scientific aspects to the ethical and legal implications of genomics technologies .Reflecting from our PubMed mining data, 2012 is a golden year for genomic technologies research (see Figure 1). Between 2000 and 2010, there were only few studies every year conducted on the topics of 'medical genomics', 'genetic discrimination' and 'genetics concerns'. The research started to blossom and reached its peak in 2012. In 2012, there were more than 1236 articles discussing 'medical genomics', nearly 487 articles on 'genetic discrimination', 572 articles on 'genetics concerns' such as genomic data privacy, and 4208 articles on 'genetic testing'. Apparently, there is an increasing interest in the benefits and challenges of genomic technologies. That leads us to a question of why there is this trend.

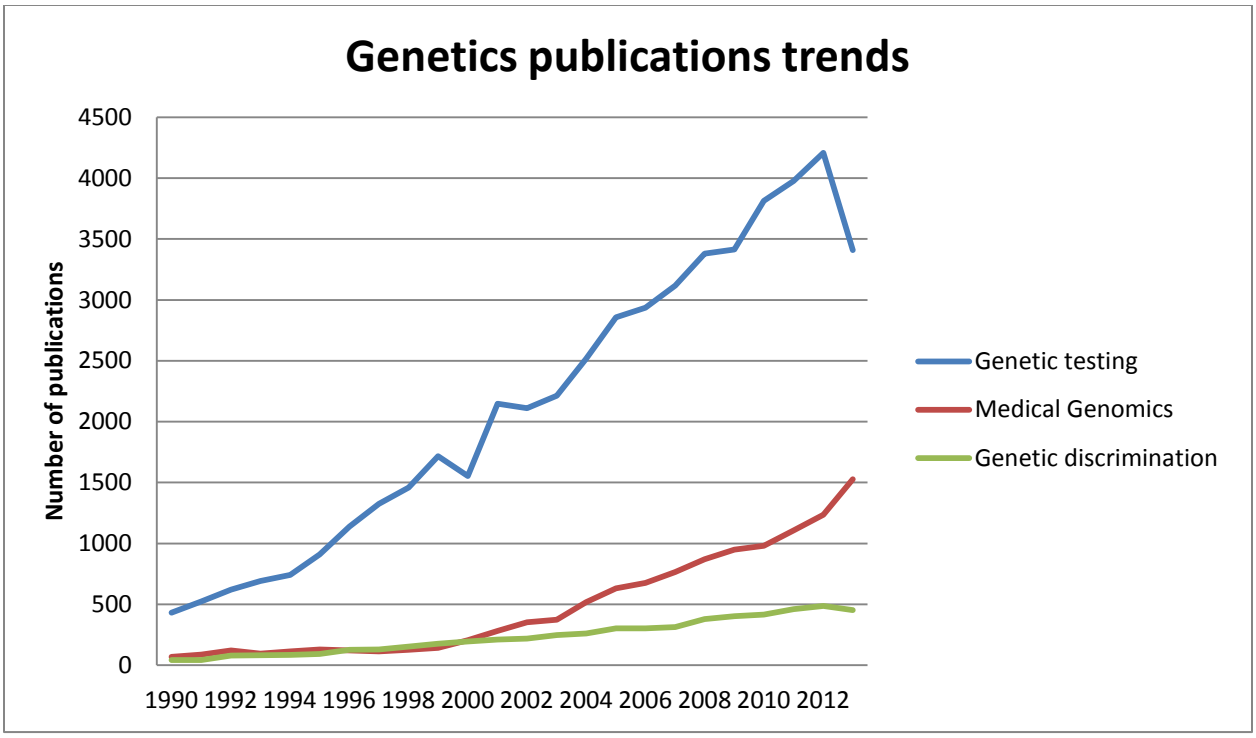

Figure 1: Genetics publication trends generated from PubMed

It all started with public polls on public opinions about the growing trend of science and technology. . In a recent poll conducted by the Huntington Post and YouGov organization on the DNA breakthroughs, the majority of Americans (38%) are excited about the main scientific breakthroughs on human, plant and animal DNA (YouGov, 2014). However, many of them are concerned about the privacy and ethics of genetic research. 34% of the surveyors strongly disapproved of scientists using DNA and cloning technology to bring woolly mammoths and other extinct species back to life (YouGov, 2014). 52% strongly disapproved of scientists using research on human DNA to produce children with unusually high intelligence or other special attributes (YouGov, 2014). Lastly, 35-37% of American surveyors are very worried about that scientists may begin to 'play God' (YouGov, 2014). This message is brilliantly made into movie Transcendence (2014) played by Johnny Depp and Morgan Freeman. The movie builds a battle

of two contradictory spectrums of ideas between the utopian technology who believes science can help cure all our illness and solves all our problems versus the dystopian technology who strongly sees science as a threat to the humanity. In a survey conducted on April 2014 by Pew Research Center about public views of science and technology, most of U.S. adults are wary of some controversial changes that may be on the near-term horizon (Smith, 2014, p. 7). On the topic of ubiquitous wearable or implanted computing devices, 53 percent of the respondents think it would be a worse future if most people are fed information by devices or implants (Smith, 2014, p. 7). 65 percent of the respondents also are against robot caregivers for elderly and infants (Smith, 2014, p. 7). 63 percent are concerned about U.S. airspace opening to personal drones (Smith, 2014, p. 7). Most importantly, 66 percent of the respondents are not in favor of the ability for parents to alter DNA of prospective children (Smith, 2014, p. 7). As a result, there are huge ethical, social and legal concerns from the public towards the development of science and technology. In the case of genetic technologies, many studies and research has been conducted on public perceptions of genetic testing in regards to their knowledge, their trust and their ethical concerns such as privacy, access and control.

In regards to public interests in genetic testing, 70-80 percent of a survey respondents indicated their willingness to pay for direct-to-consumer (DTC) genetic testing, 51 percent were willing to pay for testing for serious and unpreventable diseases and 64 percent would consider using DTC genetic testing to obtain useful health information (Caulfield & McGuire, 2012, p. 26). In another study, to measure the social networkers' knowledge in genetic testing, the researchers asked if the respondents had heard of any personal genome testing companies (PGT); and 47 percent of survey respondents reported having heard of personal genetic testing companies (McGuire et al., 2009, p. 3). However, only 6 percent of the respondents had used the

services of a PGT (McGuire et al., 2009, p. 3). Yet, 64 would consider using them in the future (McGuire et al., 2009). When asked for the reasons to do genetic testing, 81 percent of the respondents were curious about their genetic make-up and 74 percent were keen on finding out if a specific disease runs in their family or in their DNA (McGuire et al., 2009, p. 4). McGuire et al. (2009) also found out the perceived benefits of genetic testing. By getting their genes tested, 53 percent of the respondents would increase individual's control over their health; 58 percent would stimulate discussion about personal health within the family; 65 percent would take into consideration their genetic test results for their future health care decisions and 84 percent would consult a physician or modify their lifestyle by dieting and exercising more (p. 4).

On the other hand, researchers are also interested in the risk perceptions of genetic testing. Surprisingly, 42 percent of the respondents were confident in their understanding of all the risks and benefits of the PGT (McGuire et al., 2009, p. 4). In term of privacy concerns, a study recorded that 37 percent of respondents were afraid that results from a study would be used against them; 85.7 percent preferred that their samples were de-linked to their personal information; and 26 percent had concerns about the future uses of data from their results (Rachul et al., 2012, p. 7). For the access to genetic information, the same study noted that 75 percent of the respondents had concerns about governments having their samples and information (Rachul et al., 2012, p. 8). Nevertheless, the public seemed to have very much respect and trust for researchers since 77 percent of the respondents had a lot of trust in the researchers' ability to protect their information (Rachul et al., 2012, p. 8). On a similar topic of trust, Rachul et al. (2012) looked at the public perceptions of ownership and control of genetic information. There was a large sense that participants own their own samples (Rachul et al., 2012). More than that, 97 percent of the respondents were more comfortable with a university or hospital managing and

storing their samples as opposed to 6 percent were comfortable with for-profit organizations managing their samples (Rachul et al., 2012, p. 11). In another study, Caulfield (2006) found out that 53% Canadians trusted university scientists in contrast to 23% Canadians trusted researchers funded by industry (p. 1353).

With much trust and respect for researchers, the public also have a lot of expectations for physicians in helping them to understand the results. 78 percent of the respondents in the online survey would ask the physicians to interpret the results because physicians have both a professional obligation to help individual understand the results and enough knowledge to interpret the results for them (McGuire et al., 2009, p. 4). Therefore, the public take for granted that doctors and physicians are reliable and knowledgable in managing and interpreting their genetic results. In fact, 60 percent of the respondents considered their results as a medical diagnosis (McGuire et al., 2009, p. 4). Without physicians' help, genetic results could cause anxiety to individuals who get their genes tested. In a systematic review on psychological impact of testing, genetic test results could lead individuals to inappropriate behavioral response because they could overinterpret the significance of a positive result or gain a false sense of insecurity from a negative result (Caulfield & McGuire, 2012). Nevertheless, there are still doubts for the genetic test result. 53 percent of the online survey respondents did not think the information would be useful; 21 percent had doubts about the reliability of the result (McGuire et al., 2009, p. 4). Most importantly, 39 percent of the respondents had concerns about the privacy of their result (McGuire et al., 2009, p. 4). As a result, in the same study, 51 percents of the survey respondents would support federal regulations of PGT companies (McGuire et al., 2009, p. 4). In another study, 90 percent of the respondents would support a law to protect genetic data (Rachul et al., 2012). In a 2001 survey, Canadians expressed their privacy concerns over the genetic

discrimination. 61 percent and 29 percent of the survey respondents strongly agreed and agreed respectively that genetic information should be governed in a stricter manner than that of other forms of personal information (Caulfield & McGuire, 2012, p. 29). Our concerns over our genetic information are reasonable since it is our fundamental privacy right that constructs biologically who we are. In the next section, I am going to discuss the current legislation in Canada in protecting genetic information.

The inadequacy of Canadian legislation in the protection of genetic discrimination

While many Western countries such as the United Kingdom and the United States has passed laws prohibiting discrimination on the basic of genetic information, Canada is still lagging behind. It is argued that the main reason for the lack of protection of genetic discrimination in Canada is because Canada has a universal health care system, rather than health insurance. Almost every Canadian is on Medical Service Provider, Canadian government does not feel the need to impose laws or policies to regulate the private health insurance industry. However, Canadians also are very much concerned about genetic discrimination as Americans are. In a 2006 survey, 39.9 percent of Canadians who were at risk for Huntington's disease had experienced discrimination, 29.2 percent of respondents got rejected for their applications for insurance coverage and 7 percent reported employment discrimination (Watton, 2009). In a 2003 survey, 91 percent of Canadians opposed to the access of their genetic information from an insurance company or from their employers (Watton, 2009). Therefore, Canadian legislation should impose laws or policies to meet the desire of Canadians to be protected against genetic discrimination.

At this moment, Canadian law system has several ways of protecting genetic discrimination indirectly. First of all, we have the Grounds of Protection under the B.C. Human Rights Code. Our genetic information can be applied into the grounds of either ancestry, colour, place of origin and race or disability - physical or mental. For the first ground, our genetic information is somehow similar to the idea of ancestry and race.

> *Ancestry typically refers to discrimination based on one's ancestors and is often cited as a ground by First Nations people. Colour refers to skin-tone and extends protection across the full range of different skin-tones. (Human Rights Code, RSBC 1996, c. 210.)*

Indeed, our genetic information can be traced back from our ancestry, which constructs our skin-tone. Therefore, if a mutation, which can cause cancer, runs in the family gene, and we get rejected from health coverage or from a job because of the mutation; that should be considered a discrimination based on our ancestry or our race. Also, if an employer refuses to hire or promote a person with the risk of having a Huntington's disease for example, it also can be considered a discrimination on the ground of disability.

> *All major diseases and illnesses are included in the definition, such as cancer, Alzheimer's, Crohn's disease, cerebral palsy, epilepsy/seizures, heart attack, heart conditions, HIV / AIDS, arthritis, etc. All mental illnesses are included in the definition as are conditions associated with developmental delay and learning disabilities. (Human Rights Code, RSBC 1996, c. 210.)*

Above are the list of diseases and illnesses that are considered disability. However, the current legislation still does not address the concepts of future disability, perceived disability or imputed disability (Watton, 2009). Nor does it prevent the discrimination to be taken place at the first place; it only can offers remedies for damages that the discrimination has caused. As a result, the Grounds of Protection is not adequate in protecting genetic information. Furthermore, in

employment, under the anti-discriminatory model, genetic discrimination is not necessarily prohibited (Thable, 2006, p. 25). Under Canadian labour law, an employer may refuse to hire or terminate an employee who do not meet a *bona fide* occupational requirement (BFOR) (Thable, 2006, p. 25). BFOR is the most common defence to an act of discrimination in employment which is also closely tied to the corresponding duty on the employer to accommodate the individual or group affected by the discrimination. In one case, B.C. v. B.C.G.S.E.U., the SCC decided that the discriminatory standard of the employers was qualified as a BFOR, because the employer adopted the standard for a rational purpose connected to the performance of the job in an honest and good faith belief. As a result, in Canadian anti-discriminatory model, some forms of genetic discrimination in the workplace is permitted.

Another legislation regulating our genetic information is the personal information or the privacy act. As genetic information considered ancestry, race or disability, it could also be seen as our personal information. Under the Personal Information Protection and Electronic Documents Act (PIPEDA), personal information is defined as,

> *information about an identifiable individual, but does not include the name, title or business address or telephone number of an employee of an organization. (PIPEDA)*

PIPEDA only applies to private section and aims to govern the collection, use and disclosure of personal information as a protection of the right of privacy of individuals. Under section 4 of the PIPEDA, it is prohibited to collect, use or disclose personal information of an employee,

> ***4.*** *(1) This Part applies to every organization in respect of personal information that*
>
> *(a) the organization collects, uses or discloses in the course of commercial activities; or*

(b) is about an employee of the organization and that the organization collects, uses or discloses in connection with the operation of a federal work, undertaking or business.

PIPEDA is a great means to protect our personal information against any misuse in private sectors. However, there are cases that government bodies or public sectors such as university institutions or researchers or government themselves use or access our personal information in general without our consent or permission. PIPEDA does not have the jurisdiction to protect us from this public group. Therefore, we have another act called Freedom of Information and Protection of Privacy Act (FIPPA), which aims to protect personal privacy. Part III in the FIPPA clearly states the protection of personal information applied in employment in the public sector.

30 *A public body must protect personal information in its custody or under its control by making reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or disposal. (FIPPA)*

31.1 *The requirements and restrictions established by this Part also apply to*

(a) the employees, officers and directors of a public body, and

(b) in the case of an employee that is a service provider, all employees and associates of the service provider. (FIPPA)

While PIPEDA governs the private sectors in protecting our personal information, FIPPA manages the public sectors in protecting our personal privacy. However, that is still not enough protected required for our genetic information. In a 2001 survey, Canadians expressed their privacy concerns over the genetic discrimination. 61 percent and 29 percent of the survey respondents strongly agreed and agreed respectively that genetic information should be governed

in a stricter manner than that of other forms of personal information (Caulfield & McGuire, 2012, p. 29). In the next section, I am going to present my own study about the public perceptions of genetic testing conducted on Simon Fraser University students and staff.

Method

The survey was conducted with SFU Websurvey to ensure its security and reliability. For the respondents recruitment, we applied random sampling method by distributing the Websurvey link to SFU mailing list of all the school departments with the permission of their administrators. Also, this study participation is completely voluntary and anonymous; and thus, no personal information such as names, addresses, telephone numbers or email addresses of the respondents are obtained. The population for this study is adult at consenting age in British Columbia. The survey was launched on May 26 and closed on July 23. Its link was sent to different mailing lists to SFU departments including Communication, Health Sciences, Criminology, Psychology, Political Economy, Public Policy and International Studies and other social media platforms such as Facebook and Twitter of SFU Communities. The goal of the survey is to find out the answers for these three research questions:

Q1. How familiar is the public on the topic of genetic testing?

Q2. How concerned are the public towards their genetic information regarding to privacy, access and control?

Q3. What are the impacts of genetic testing on health care system and on women?

Results

Respondents (Independent variables)

Respondents (N = 100; males n = 37%; females n = 63%, other n=1%) are students and staff at Simon Fraser University from different departments and faculties. For the independent variables from the respondents, we are mainly interested in looking at their age, majors, political views and ethnicity. In this study, the majority of our respondents are between 21 to 24 (40%) with the racial background of White (61%) and majoring or working in the field of Arts and Social Sciences (43%) or Communication, Art and Technology (40%). For political views, 11 percent of our respondents are Conservative, 35 percent are New Democratic Party and 14 percent are Liberal. Another important finding in this study is that our respondents follow news about science and medicine not closely at all (17%), not too closely (51%), somewhat closely (26%) and very closely (7%).

Dependent variables

The main themes of genetic testing of this study are: the knowledge and attitude of the public towards genetic testing and government legislation regulating, the impact of genetic technologies on women, the health system implications, the privacy concerns over genetic information including access, control and trust, and the ethical implications of genetic testing.

Knowledge

Five topics related to genetics and biotechnology are used to test the knowledge or the level of familiarity of the respondents towards genetic testing: genetic testing, prenatal testing, designer babies, biobank and stem cell research. The majority of our respondents only know something,

not much about genetic testing (71%), prenatal screening (66%), designer babies (47%), biobank (39%) and about stem cell research (72%). There is just a small portion of the respondents who know a great deal about genetic testing (21%), prenatal screening (18%), designer babies (9%), biobank (7%) and stem cell research (11%).

The survey also examines the knowledge of the respondents about government legislations of genetic testing and genetic technologies. 66 percent of our respondents do not know if the government regulates genetic testing. The other 20 percent of the respondents think that the government regulates genetic testing while 15 percent do not think so. We see the similar trend for genetic technologies. 64 percent of our respondents are unsure if the government regulates genetic technologies. While 22 percent reckons that the government does regulate genetic technologies, 15 percent reckons the opposite thing.

Impact of genetic technologies on women

The survey tackles on topics related to the use of genetic technologies on women including the diagnosis of BRAC 1/2, the possibility of double mastectomy and in vitro fertilization, the process of helping women to become pregnant by biotechnology. When asked if our respondents are aware of the Angelina Jolie event of conducting double mastectomy to remove her high risk of having breast cancer occurred May, 2013, 78 percent of our respondents know about this event. A follow-up question to this event are if the genetic test showed that the respondents were carrying the BRAC1 or BRAC2 gene which might cause them breast cancer or ovarian cancer, would the female respondents conduct (double) mastectomy operation as Angeline Jolie did? Also, from a male perspective, would our male respondents support their female partners/relatives/friends to conduct the mastectomy? 38 percent of our respondents

would conduct or support the mastectomy and 40 percent of the respondents are unsure about their decision for this scenario. Also, 22 percent of our respondents oppose the idea of conducting the mastectomy. Furthermore, when asked if the respondents have considered or know anyone who have considered becoming pregnant by using in vitro fertilization, the majority of them (56%) do seem to be familiar with this fertilization technology.

Health system implications

One of the most interesting topics this survey is trying to find out is the implications of genetic testing on the health system. First, we would like to understand the value of genetic test result to our respondents. 39 percent of our respondents consider genetic test result as a medical diagnosis (Figure 2). Secondly, we also try to find out how the respondents would understand the genetic test result which might be technical. Not surprisingly, 88 percent of our respondents would ask the physician to interpret the genetic test results for them. Within this 88 percent, 32 percent of them think that physicians have enough knowledge to interpret the results for them, 56 percent of them see that physicians have a professional obligation to help individuals understand the results (Figure 3).

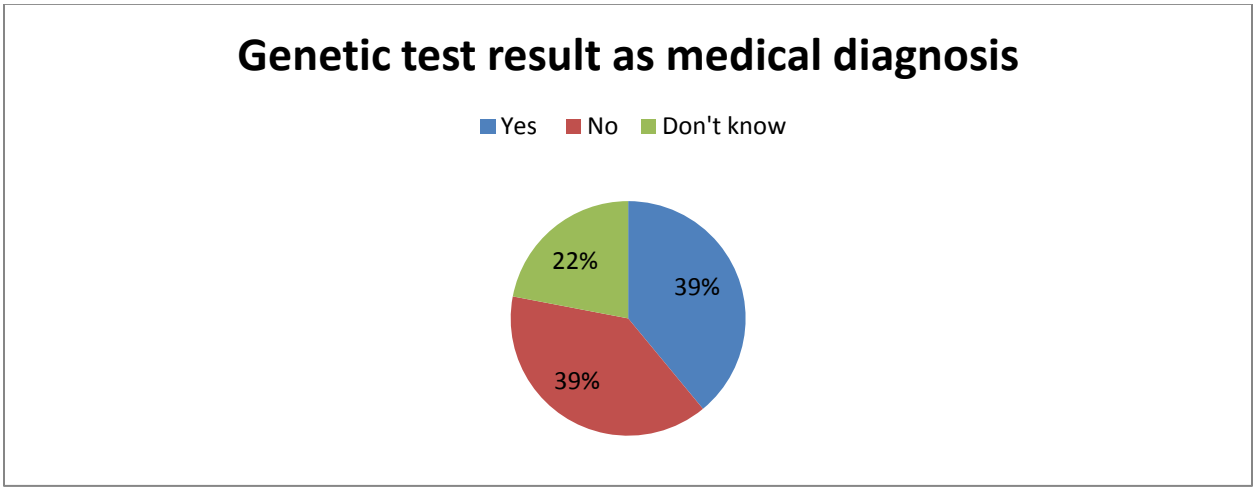

Figure 2: Respondents' views on whether they consider genetic test result as a medical diagnosis

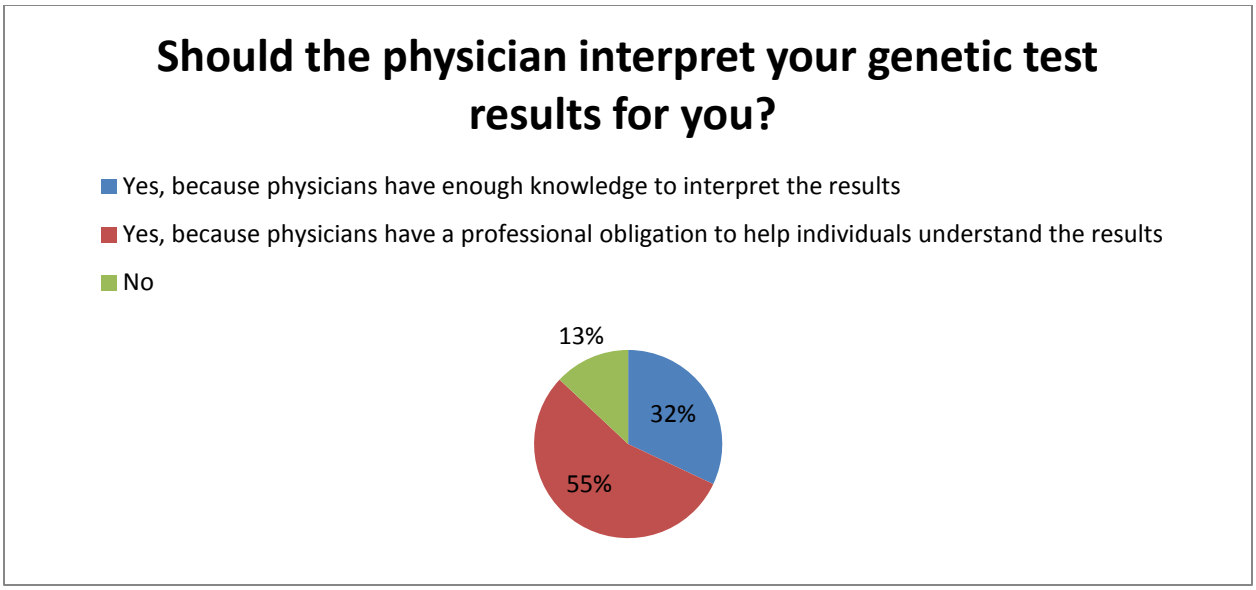

Figure 3: Respondents' views on whether the physician should interpret their genetic test results

Privacy concerns including access, control and trust

For this topic, we ask our respondents how much they trust for these categories to access their genetic test results: doctor/physician, family members, researchers funded by private sector or industry, researchers from public hospitals or universities, law enforcement, health insurer and employer (Figure 4). The results reflect that doctor and physician receive the most trust from the public (83%) with some and a lot of trust. Family members come second after doctor physician with 78 percent of some and a lot of trust from the public. Researchers funded by private sector or by industry seem to receive none and just a little trust from the public (74%). On the other hand, researchers funded by public hospitals or universities receive a more positive trust than those funded by private sector with 57 percent of some and a lot trust, while the latter only receives 24 percent of some and a lot of trust from our respondents. The last three categories receive negative trust from the public. 79 percent of our respondents do not trust or just at a low level of trust for law enforcement. For health insurer and employer, 94 percent and 96 percent

respectively of our respondents have no or low trust for them to access their genetic test results. This implies that the public are very cautious of who gets to control their genetic data.

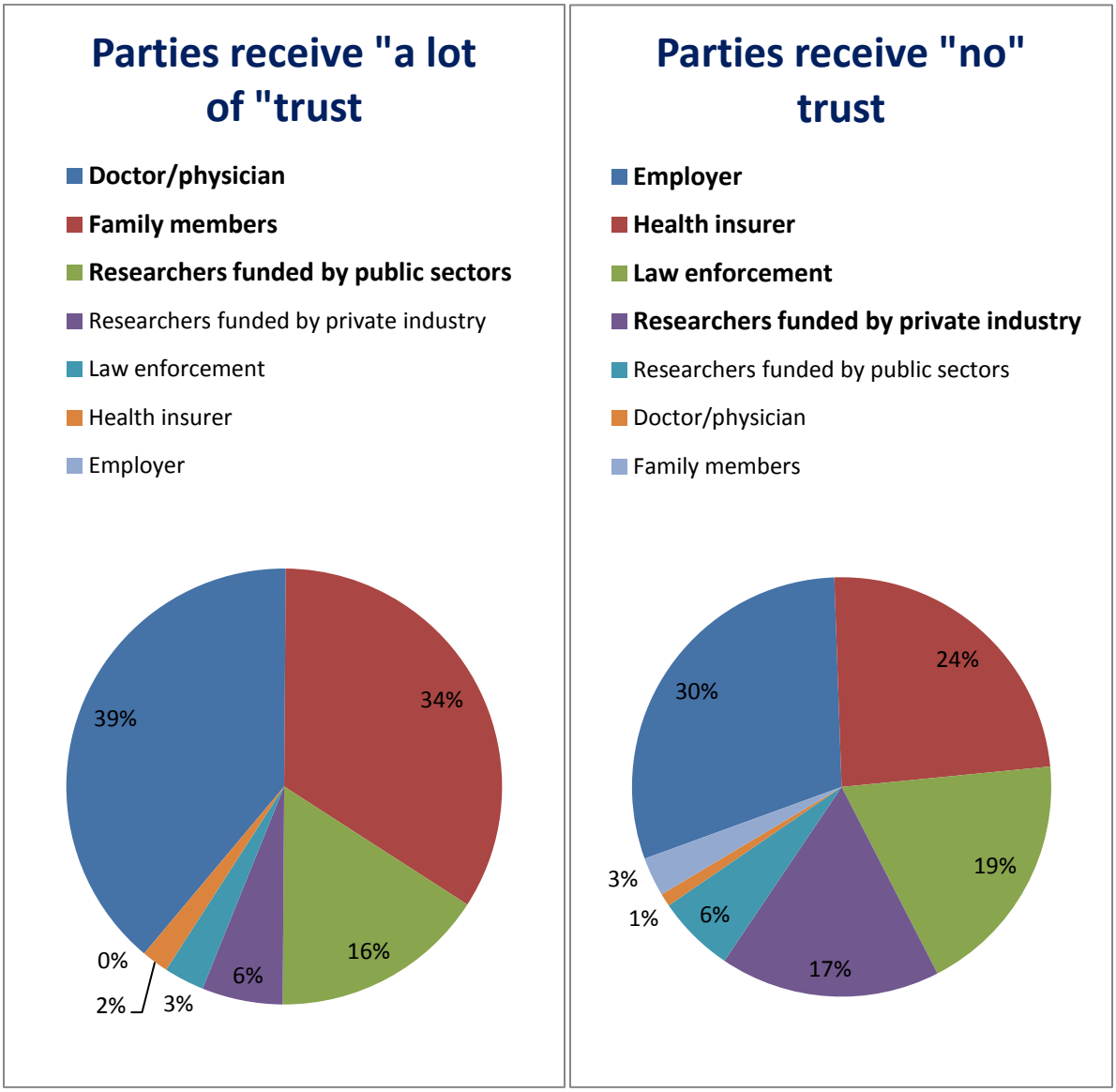

Figure 4. Respondents' trusts for accessing and controlling their genetic data

We also examine our respondents the degree of concern about privacy for their genetic information and about the use of their genetic information (Figure 5). 83 percent of our respondents are concerned and very concerned about the privacy of their genetic information. 86

percent of them strongly disagree and disagree that we should allow researchers to share our personal information or personal identity with our genetic samples with the public. As a result, 58 percent of our respondents agree and strongly agree that laws/policies/rules governing the protection of our genetic information should be stricter than for other forms of personal information.

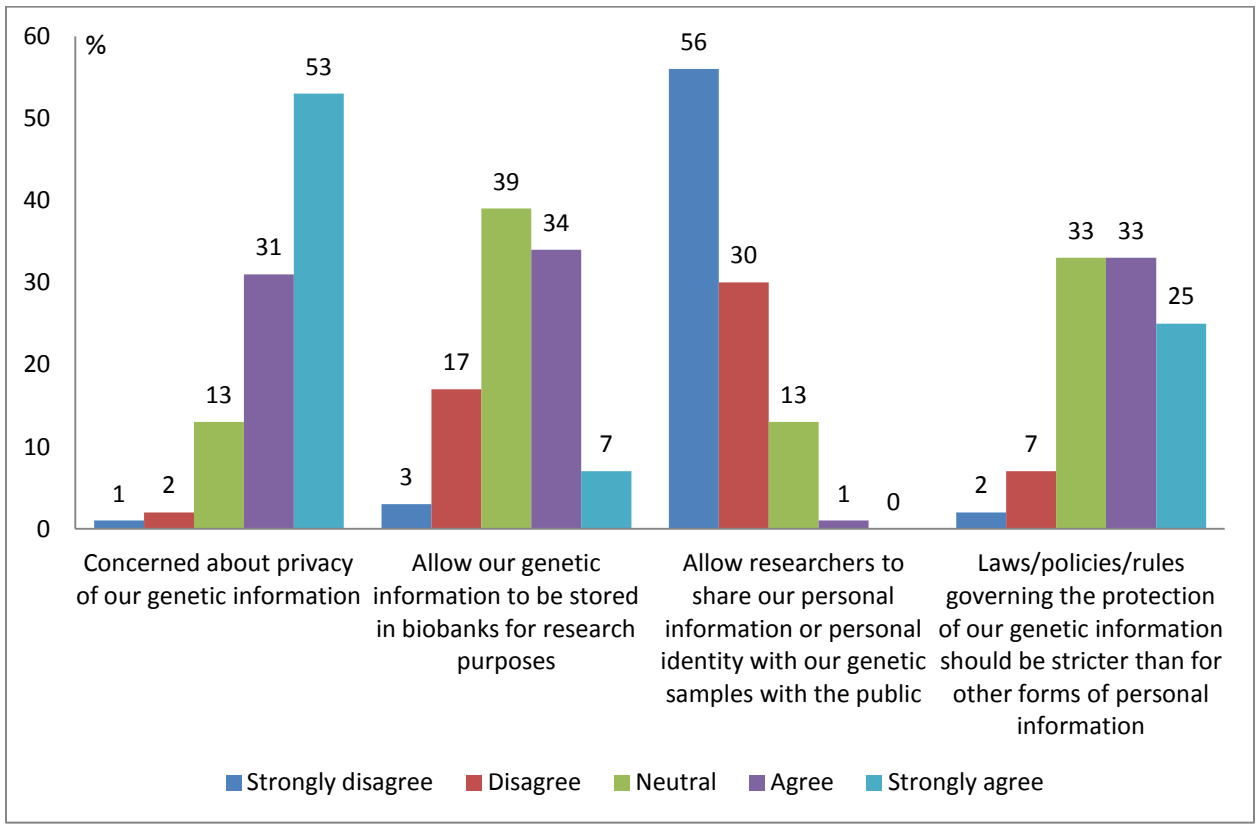

Figure 5: Respondents' attitudes towards their genetic information

Ethical implications of genetic testing

The Likert scale from one to five, in which one is completely unethical, and 5 is completely ethical, are used for the respondents to rate the ethical level of the different uses of genetic information (Figure 6). 94 percent of our respondents think that it is completely unethical for employers to request genetic profiles from prospective employees before deciding to hire them

or not. Likewise, 86 percent of our respondents rate that it is also completely unethical for health insurance companies to require genetic information before deciding on the cost of health coverage. In addition, the concept of 'open consent', which researchers can use our genetic information in their research study without our informed consent, is also completely unethical and unethical to 76 percent of our respondents. Also, 75 percent of them are against the idea of patent law that is applied to human genetic material, which means we can buy a patent for our genetic material.

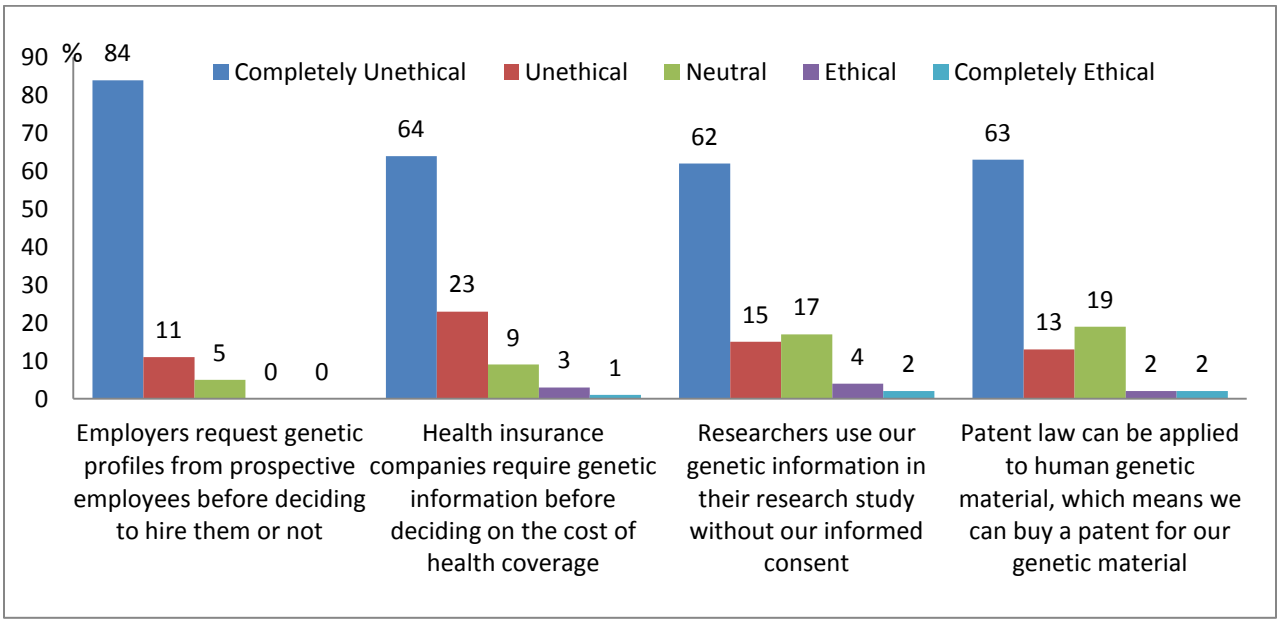

Figure 6: Respondents' attitudes toward the use of their genetic information

Interesting Correlations

Political views on genetic testing

One of the goals of the survey is to produce both quantitative and qualitative data by using Excel to code close-ended questions and applying SPSS to analyze crosstabs between different variables. The first cross tabulation is the political perspectives on the role of government in

genetic testing. We ask our respondents for their general political views and their thoughts on whether the government should regulate genetic testing and/or genetic technologies (Fig. 7). The results are quite consistent. Within the biggest parties in Canada, the Conservative party has the least support for government regulation of genetic testing (63.6%) or genetic technologies (44.1%). To the left spectrum of political views, Liberals are a huge supporter of genetic testing (64.3%) and genetic technologies (50%). Likewise, New Democratic Party is the biggest supporter for government regulations of genetic testing and genetic technologies (71.4%).

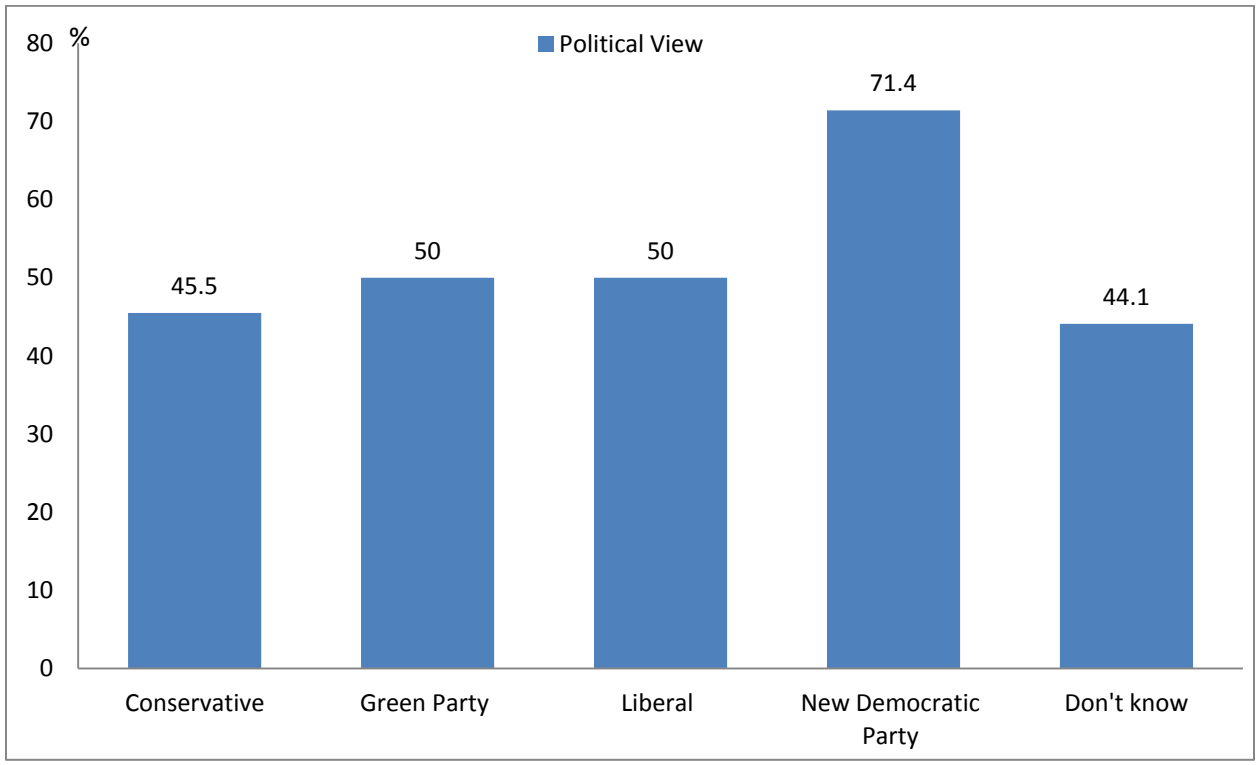

Figure 7: Relationship between political views and whether government should regulate genetic testing

As a result, it is not surprising to find out that these political views also have different support for laws/policies/rules governing genetic information to be stricter than that of our personal information. 35.7 percent of Liberals respondents agree to the need for a stricter law regulating our genetic information. Likewise, 37.1 percent of NDP respondents also agree with

the statement above. Green Party of Canada is the biggest supporter for Not surprisingly, only 18.2 percent of Conservatives agree that laws regulating genetic information should be stricter than that of our personal information.

Age and privacy concerns over genetic information

The second correlation we are interested in matching up is the relationship between age and their concerns about the privacy of their genetic information (Fig. 8). In general, all the ages group are concerned or strongly concerned about their genetic information, but the age group from 50 and above are the most concerned one. 100 percent of our respondents aged from 50 and above are concerned or strongly concerned about their genetic information. Interestingly, 85 percent of the young people aged from 21-24 are also concerned and very concerned about their genetic information. This is a good news because they are the future of our society and their concerns will reflect which directions our society is going to grow to protect the privacy of the genetic data. 77 percent of respondents aged from 25-29 are also in the same state of mine for their genetic information. 80 percent and 75 percent of age group 30-40 and 40-50 respectively are also concerned and very concerned about their genetic information. These trends show a high awareness of populations at all ages about the privacy issues related to their genetic information.

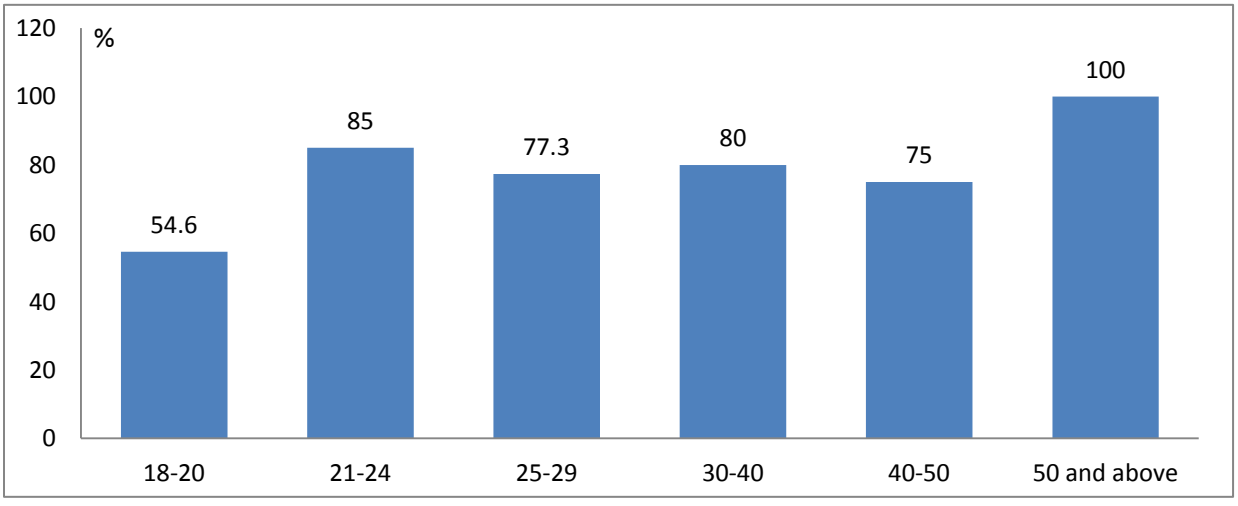

Figure 8. Relationship between age and genetic information privacy concerns

Gender views on designer babies

In addition, we match up our independent variable, gender, with our dependent variable, the ethics of designing babies with desirable traits (Fig. 9). In general, 74 percent of our respondents are opposed to the use of genetic testing for parents to design their unborn babies with all desirable traits such as high intelligence or strength. Astonishingly, female are more against the idea of designing babies than male. 76 percent of female respondents oppose/strongly oppose 'designer babies'. On the other hand, only 62.1 percent of male respondents strongly oppose 'designer babies'. This reflects that gender affects their attitudes and opinions toward genetic technologies and scientific innovations. This is a new worthwhile area for research.

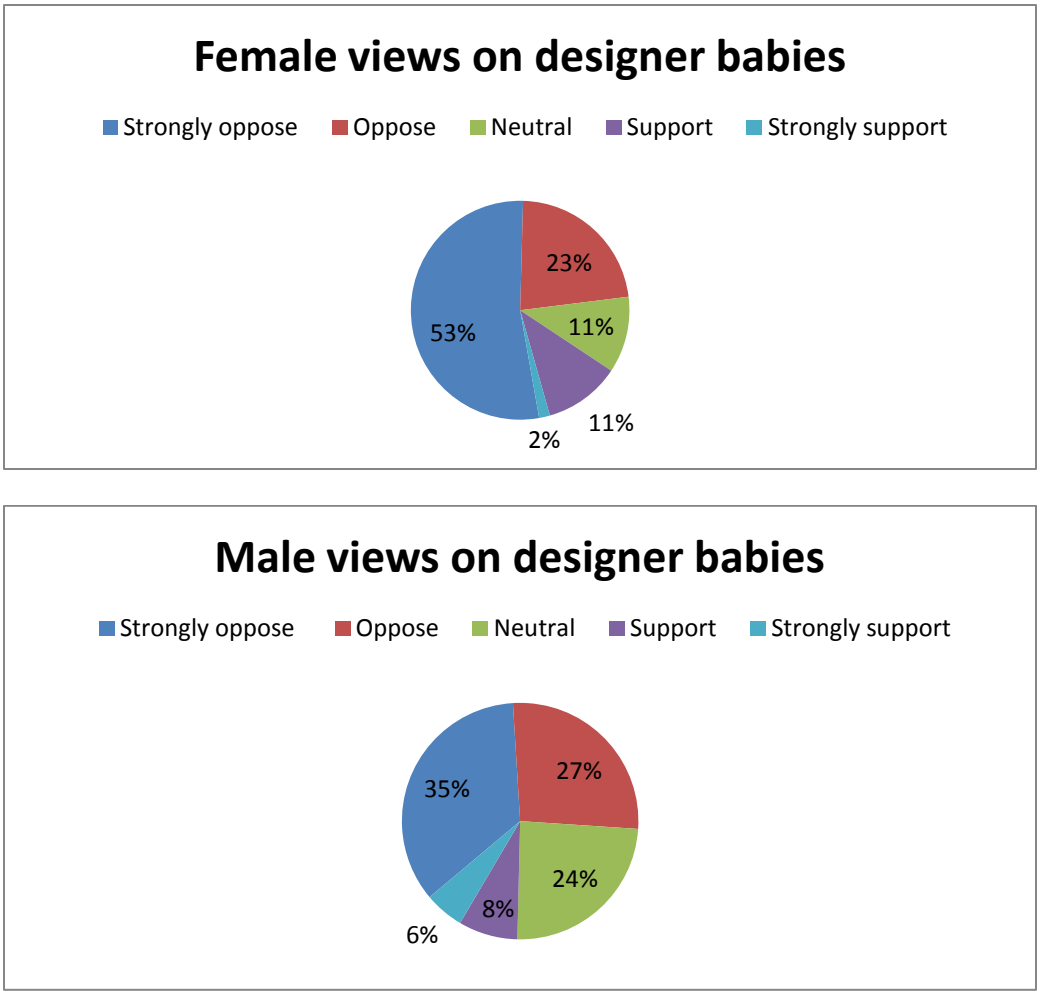

Figure 9. Relationship between gender and designer babies

The Angelina effect

The most important correlation we try to measure is the impact of Angelina Jolie's double mastectomy story on the decision of the public to conduct the operation in a hypothesis scenario. With this correlation, we ask our respondents whether they are aware of the event which Angelina conducted a double mastectomy to eliminate her risk of having breast cancer and ovarian cancer (Fig. 9). Also, we asked our respondents a hypothesis that if they were diagnosed with the gene mutation BRCA1 or BRCA2, would they undergo the (double) mastectomy? If the respondent is a male, would he support his female partner/relative/friend to conduct the mastectomy? 77 percent of our respondents were aware of the event and 22 percent did not know about the event. Within that 77.5 percent of the respondents who were aware of the event, 42.9 percent of them would conduct (for female) or support (for male) the mastectomy operation if the BRCA 1/2 showed up in their genetic tests. In fact, also a large number of our respondents do not know what to do if they were diagnosed with BRAC1/2. 40.3 percent of respondents who knew about the Angelina event, were not sure which action to take. The majority of the respondents who did not know about the Angelina event, also were not sure whether or not to undergo mastectomy (40.9%). As a result, celebrities such as Angelina Jolie can help raise awareness about genetic testing and genetic technologies; but her story cannot provide enough genetics literacy for the public to fully understand how genetic test results actually work.

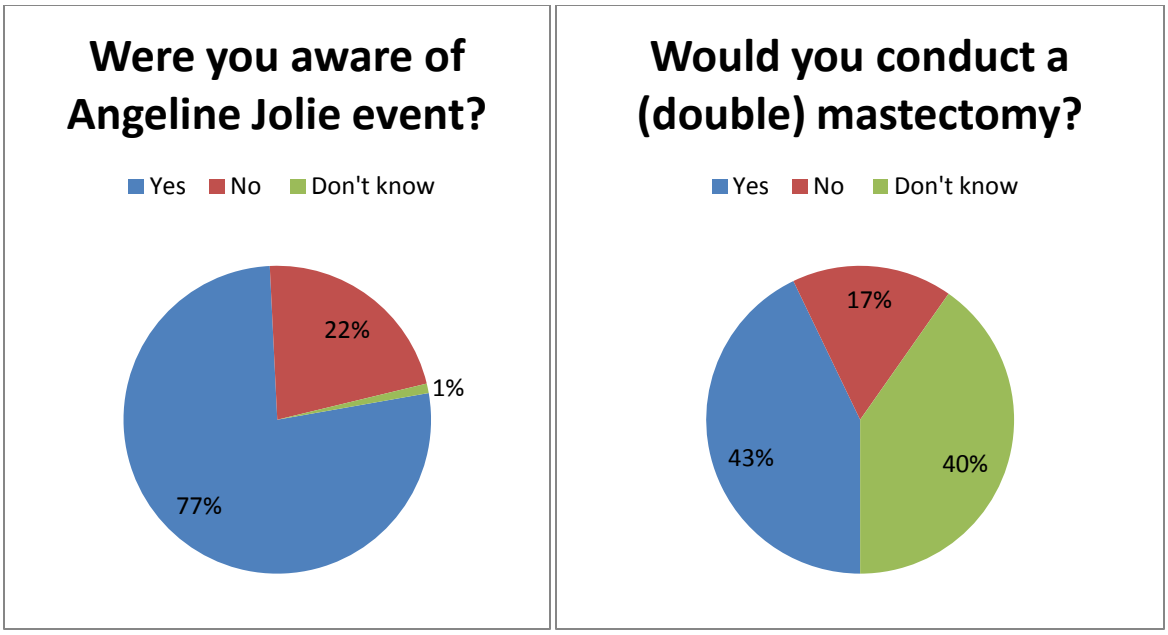

Figure 10: Relationship between respondents' awareness of Angelina event and their attitude toward double mastectomy

Discussion and Conclusion

This study explores the wider sociocultural and political aspects of genomic science in our society today. There are many controversies around genomic science such as privacy concerns around our genetic information; access, control and trust issues of genetic information; genetic discrimination in health care or in employment; and the ethics of genetic technologies in the use of designing babies. Bioethics is always a complicated matter, which requires an approach that is essentially sociological rather than philosophical (Franklin & Roberts, 2006, p. 3). In the social sciences of genomics, we do not tend to work toward identifying the best or definite "answer" to a particular question as in natural science or medicine. In contrast, we look at a holistic picture in which both questions and answers reveal their specific patterns. The survey sought to find specific patterns in public perceptions of genetic testing. Yet, there are no absolute "right" or "wrong" values to these patterns. If our genetic information could be used in the study for the

cure of cancer, should we be worried about the privacy of our biological identity and not give out our genetic information? Or if genetic technologies such as preimplantation genetic diagnosis could be applied to save the life of a child by eliminating a bad gene mutation, should we argue that it is unethical to design a baby with a healthy trait? Genomic science is such "a very grey area" that its benefits and its risks can actually have the same weight. Despite genetic testing as a scientific subject, multiple 'social dimensions' of it need to be addressed by turning to these 4-W questions: "Who are the new genetic technologies for? Who benefits from them? Who loses out? What are the forms of power and inequality that are channeled through geneticization, genetic determinism or the "new genetic essentialism" (Nelkin & Lindee, 1995)" (Franklin & Roberts, 2006, p. 197)?

The results of this survey have shown that the majority of our population recognizes the importance of genetic testing and genetic technologies. In addition to that, all age groups of our respondents are very concerned about the privacy of their genetic information. Therefore, they feel the need for the government to regulate genetic testing and genetic technologies in order to protect the ethics and concerns surrounding the use of their genetic information. Most of our respondents are interested in getting their genes tested in the future. They also strongly support the use of genetic technologies to find new ways to diagnose, prevent or treat diseases such as making personalized medicine or early diagnosis of a child with a serious genetic disease. Also, a large number of our respondents have some or a lot of trust for their doctor/physician. For researchers, the public have a bit of skepticism since a large number of the respondents have no trust for researchers funded by private sector or by industry, but some trust for the ones funded from public hospitals or universities. This has led to the bulk of our respondents supporting government regulation of genetic testing and genetic technologies. We also find that respondents

with a more left wing political views like Liberals and New Democratic Party tend to favor more government regulations of genetic science. This makes a perfect sense in the context that left-wing political parties are in favor of more government regulation and intervention in economy, social welfare and society as a whole in the contrast with the "invisible hand" approach of the right wing political parties. However, the majority of our population do not support genetic law to be stricter than other forms of personal information; they are more inclined to stay neutral on this topic. Our finding is contrasted with Caulfield's result that 61 percent and 29 percent of their survey respondents strongly agreed and agreed respectively that genetic information should be governed in a stricter manner than that of other forms of personal information (Caulfield & McGuire, 2012, p. 29). In other words, our respondents agree with the need for government to regulate genetic science but not in a stricter manner. This might result from the structure of our population who are university students, faculties, and staff, otherwise known as, researchers and scholars. Whether scientists and researchers support strict regulations on research involving human subjects is also a complex issue worth digging into.

The next stage of getting your gene tested is to receive and interpret the results. In an article written by a genetic testing consumer of 23andMe, Cyrus Farivar (2014) shared with us that the complicated thing about the whole process is not to spit our salvia into a tube and mail it to California where 23andMe is based for analysis. The tough part is how to understand the result. Farivar (2014) stressed that the genetic result he received was technical with no detailed analysis and no consultation for the consumer. Even his family physician or local hospital doctor could not interpret the diagnosis for him. In fact, in a study of physicians' attitudes about multiplex tumor genomic testing, physicians have low genomic confidence and they are not sure how to incorporate predictive multiplex somantic genomic tests into practice, and they are

uncertain about the disclosure of genomic information (Gray et al., 2013). However, our respondents are mainly unaware of these facts. A large number of our respondents consider genetic tests as a medical diagnosis, and the majority of them assume that doctors/physicians should interpret their genetic test results because either they have enough knowledge to interpret the results or they have a professional obligation to help individuals understand the results. Genomic science is still a new branch of bioscience; and therefore, most physicians or doctors are not fully equipped with expertise about genomic data or information. This situation is quite similar to the scenario where physical education teachers have to give sex education in high schools while their expertise is completely not about sex-related topics. As a result, it is recommended that direct-to-consumer testing companies should offer consultations for their consumers to fully understand their genetic results. This also gives rise to the need for more genetic counsellors in order to assist both consumers and physicians in knowing what actions they should take with the results, because if we do not really understand the genetic test result, we might go down the wrong track.

In the case of mastectomy, it is an interesting scenario to examine both the understanding and expectation of our respondents towards their genetic test results as well as the Angelina Effect and whether Angelina's double mastectomy has a positive impact on its audience. 77 percent of our respondents could recall the news about Angelina undergoing a double mastectomy to prevent her from having breast cancer and ovarian cancer in May 2013. As a result, if they were put in the same shoes as Angelina where the gene mutations BRAC1/2 showed up in their genetic test results, the majority of our respondents either would conduct the mastectomy as Angelina did or they would not know what to do. These two answers both imply a problematic hole in the genohype in which the media reports genetics in an inaccurate and

unrealistic way. First of all, a genetic test result is far from a medical diagnosis. To examine whether you have the BRAC1/2 gene mutation, to know exactly the chance for the mutations to develop breast cancer you have to go through a much more complicated and expensive testing process which can cost up to $3000. A simple test done at 23andMe cannot tell you for sure if you will have breast cancer. On average, women who carry BRAC mutations have about a 65 percent risk of eventually developing breast cancer; but for most women, the rate of the risk is about 12 percent (Grady, 2013). With this misunderstanding in mind, 21 percent of the mastectomies were conducted on women whose lumps were small enough that those major operations for early breast cancer was needless or unnecessary (Donelly, 2014). Therefore, when a large number of our respondents agree to undergo a mastectomy if their genetic test results diagnose them with the BRAC1/2 mutations, that is not a rational decision. On the other hand, the majority of our respondents are not sure how to react to the result. That indicates Angelina did raise more awareness for the public to know and accept the norm of mastectomy but she could not provide enough knowledge and guidance for the public to be fully informed in this topic. Angelina Jolie is a wealthy and powerful celebrity; she has a whole team of experts and counselors helping her make decisions. As regular people, we do not have the resources and access she has. Therefore, the public needs to have a good understanding about genetic testing and sufficient guidance from the healthcare system to make the right decisions with their genetic results.

Another product, which genomics science can generate, is the application to design babies. In the case of ‘designer babies’, it is an unethical act in the eye of many of our respondents. 74 percent of them strongly oppose and oppose parents to design their unborn babies with all desirable traits such as high intelligence or strength. Female respondents tend to

have a bigger aversion towards the idea of designing babies. This might result from the representation of the media about the biotechnology as them 'playing God'. Many of the news coverage about designer babies carry a dystopian view of technology. Designer babies are portrayed to be superhuman, too clever, too fast, and too happy; and that poses a threat to our humanity, which terrifies people. ‘Designer babies’ are seen as the product of ‘genetic manipulation’ that could alter the fundamental self-understanding of human beings, break down the modern conceptions of law and morality, and transform the normative foundations of social integration (Franklin & Roberts, 2006, p. 28). This is a problematic thought. First of all, it is problematic starting from the word ‘design’. Technically, ‘designer babies’ involves the process of embryo selection based on genetic information and morphology and the ability to diagnose the presence or absence of a known, single, and specific mutations (Franklin & Roberts, 2006, p. 32). As a result, ‘designer babies’ are not only applied to produce superhuman, it can be applied to save a human life. In the U.K. in 2002, to save the life of their chronically ill son, Raj and Shahana Hasmi decided to design a new baby in order to use his bone marrow. This raised a huge ethical and legal debate whether the Hashmis had the right to design a “savior sibling” for their older son, in other words, to exploit the newborn child for the sake of the older one. Who gets the right to answer yes or no to that debate? What if it happened to your own child and it is the only way to cure his illness, what would you choose? Genomic technologies need to be regulated but in a flexible and personalized way that everyone who seeks its help can receive the right treatment.

Out of all the issues discussed above, bioethics is the biggest challenge for genomics science. 84 percent of our respondents agree and strongly agree that we should be concerned about the privacy of our genetic information. Therefore, our respondents have much skepticism

towards the use of their genetic information. 87 percent of them strongly disagree and disagree that we should allow researchers to share our personal information or personal identity with our genetic samples with the public. More particularly, the use of genetic information in employment and insurance received much criticism. 94 percent of our respondents consider it completely unethical and unethical for employers to request genetic profiles from prospective employees before deciding to hire them or not. 86 percent of them also think it is completely unethical and unethical for health insurance companies to require genetic information before deciding on the cost of health coverage. As a result, 93 percent of our population strongly oppose and oppose employers making decisions about hiring and promotion based on genetic testing results, a 86 percent also strongly oppose and oppose health insurance companies determining who to insure or how much to charge based on genetic testing results. In Canada, currently there are no laws to regulate the use of genetic test results by insurance companies. The Canadian Life and Health Insurance Association's (CLHIA) Position Statement claims that an insurer would not require an applicant for insurance to undergo genetic testing but if the test has been conducted and the information is available, the insurer has the right to request access to that information. However, in July 2014, The Office of the Privacy Commissioner of Canada requested that life and health insurance companies expand upon a current voluntary moratorium on asking applicants to undergo genetic tests and to not inquire about their results at all (Dmitrieva, 2014). The reason for the Privacy Commissioner to issue that statement is that it is not clear that the collection and the use of genetic test results by insurance companies is demonstrably necessary, effective, proportionate, or the least intrusive means of achieving the industry's objectives (Dmitrieva, 2014). The Privacy Commissioner also realizes that the nature of the genetic test results are highly sensitive with low predictive value. Also, it wants to encourage individuals to voluntarily

participate in health research without fear that their test results will be used one day against them such as their ability to obtain insurance. There is also evidence that restricting insurers from access to applicant's genetic test results would not have a significant adverse impact on the industry. However, this has led to a huge opposition from the Canadian Life and Health Insurance (CLHIA) Association. This is going to be a tough and brutal battle between the Privacy Commissioner and the CLHIA, a battle between the public interest and the commercial interest.

All in all, our study leads us to the answers of the three research questions (page 22). First of all, Canadians are very concerned about the privacy of their genetic information. However, they do not have a good knowledge about genetic testing or genetic technologies. Secondly, They also tend to trust publicly-funded institutions than the privately-funded for accessing of our genetic information. Lastly, there is an increasing need for genetic counsellors in our health care system and genetics/genomics literacy for physicians and doctors in order to assist patients better with their genetic test results.

The biggest constraint of this research is the limited diversity in our respondent demographics. It is mainly dominated with females, white, aged from 21-29 and majored in either Arts and Social Sciences or Communication, Art and Technology. Thus, it does not reflect the diversity of British Columbia's population, which is famous for its multicultural ethnicities. Time and budget are also the limitations for this research. We only had four months to conduct the research, and thus, there might be mistakes and errors in the process of data collection and analysis. In all, the social study of genomics science is such a new area that it requires tremendous effort to be put into research in order to produce robust but holistic policies and bioethics for the study, the use and the application of genetics. For further research, it is a great

idea to look into the conflict between the Privacy Commission and the CLHIA to come up with solutions or directions that can satisfy both parties and interests. Also, the impacts of genetic technologies on women, fertilization and 'designer babies' deserve more attention in research. In conclusion, humans have always been trying to conquer the world and control Nature by the domination of scientific discoveries. As a result, science is always embedded with human ideologies and purposes; and not surprisingly, it is also a form a social control and social inequality. Genomics science itself is a wonderful invention that can drive the human race forward. It should not be considered a threat to our humanity. Technology is not the one to blame. It is social desires that race far ahead of technology.

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APPENDIX A

Online Survey Protocol

Thank you for participating in our survey. Please note that this survey will take approximately 15 minutes to complete. Our survey aims to explore the perceptions of genetic testing on multiple themes among the population in British Columbia. With the popular trend of genetic testing today, individuals can learn about their ancestry and genes to prevent any potential health risks. However, there are many risks and concerns accompanied with the benefits of genetic testing. Could you interpret your own genetic testing result? Are you concerned about the privacy of your genetic information? Who gets to control your genetic data? This research is hoping to provide information and analyses that will be useful towards improving the ethical and procedural guidelines for governing genetic information.

Informed Consent: The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants. Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics, Dr. Jeff Toward by email at jtoward@sfu.ca.

Title of study: Public perceptions of genetic testing

Principal Investigator: Dr. Peter Chow-White (petercw@sfu.ca), Associate Professor of Communication

Co-investigator: Ha Vu Tien Dung (dungh@sfu.ca), BA Candidate of Communication.

The purpose of the study is to explore the public perceptions on multiple themes of genetic testing in British Columbia in order to contribute to the policymaking process of bringing genomics technology from the lab setting into the healthcare system. The procedures to be used in this study is to complete an online survey with a set of 32 questions. The personal risks to you in taking part in the study are minimal or none.

The benefits of study to the development of new knowledge**:** We hope to understand the public perceptions on the benefits, the risks and the challenges of the genetic testing that can have impacts on any of us. We anticipate that you will have the opportunity to contribute to the knowledge base around genetic testing and genetic information. Your output in this survey can play a key role in structuring laws and policies to protect our genetic information against any misuse or discrimination.

Our statement of confidentiality is that the confidentiality of your participation will be maintained to the extent allowed by the law. The electronic research data will be stored in a secure Canada-based server. Other research data and material will be stored in a locked file cabinet in the School of Communication. Any descriptive information that might

serve to identify participants will not be used in any reports, presentation or publications of the study. You will not be named in any reports from this study. Your participation will be anonymous and confidential. Names will be kept strictly confidential. You may withdraw your participation at any time. If you have any complaint, you can contact our Principal Investigator or Co-investigator directly. Or you can also register your complaint with the Director of the Office of Research Ethics: Dr. Jeff Toward Director, Office of Research Ethics Office of Research Ethics, Simon Fraser University, 8888 University Drive, Multi-Tenant Facility Burnaby, BC V5A 1S6, Email: jtoward@sfu.ca, 778-782-6593. If you have read and understand the risks and contributions of your participation in this study, you can indicate your agreement in the following question. Do you agree to participate in the research study described above?

Q1 . Do you agree to participate in the research study described above?

- Yes
- No

Section A - Background information

Q2 . How old are you?

- 18-20
- 21-24
- 25-29
- 30-40
- 40-50
- 50 and above

Q3 . Would you classify yourself as:

- Female
- Male

- Other

Q4 . What faculty are you in?

- Applied Sciences
- Arts and Social Sciences
- Beedie School of Business
- Communication, Art and Technology
- Education
- Environment
- Health Sciences
- Science
- Undeclared

Q5 . In Canadian politics, which political party would represent your political views best?

- Conservative Party of Canada
- New Democratic Party
- Liberal Party of Canada
- Bloc Québécois
- Green Party of Canada

Q6 . Would you describe yourself as:

- Aboriginal People/First Nations
- Asian

- Black/African American
- Hispanic/Latino
- White/Caucasian
- Pacific Islander
- Other

Section B - Knowledge and attitudes towards genetic testing and government legislation regulating it

Q7 . How closely do you follow news reports about developments in science and medicine in the last month?

- Very closely
- Somewhat closely
- Not too closely
- Not closely at all
- Don't know

Q8 . Following is a list of a few topics in genetic testing or genomic technology. How much have you heard or read about each of them?

	Don' know	Nothing	Something, not much	A great deal
Genetic testing, also known as DNA testing, allows the genetic diagnosis of vulnerabilities to inherited diseases, and can also be used to determine a child's parentage or in general a person's ancestry :				
Prenatal screeening, testing for diseases or conditions in a fetus or embryo before				

it is born :				
Designer babies, using research on human DNA to produce children with no diseases, unusually high intelligence or other special attributes :				
Biobank, a type of biorepository that stores biological samples (usually human) for use in research that gives researchers access to to data representing larger numbers of individual people than could be analyzed in previously used systems. :				
Stem cell research, the biological properties of stem cells, with the focus on scientific research, and the potential use of stem cells in treating disease. :				

Q9 . The next few questions will be about genetic testing. Have you ever heard of any genetic testing services/companies?

Yes

No

Q10 . If your answer was Yes in the previous question, could you please specify which genetic testing services/companies you've heard of? Otherwise, please leave it blank. Thank you.

Q11 . Have you, or has anyone in your immediate family, ever had a genetic disease?

- Yes
- No
- Don't know

Q12 . Have you, or has anyone in your immediate family, ever had a genetic test?

- Yes
- No
- Don't know

Q13 . Would you consider having your genes tested in the future?

- Yes
- No
- Don't know

Q14 . What are the factors that can lead you to do genetic testing?

- To understand about my genetic make-up
- To see if a specific disease runs in my family or is in my DNA
- To participate in a study for the public good on human genetics or human genome
- Other

Q15 . Please specify if your answer was "Other" in the previous question. Otherwise, please leave it blank.

Q16 . What are the factors that can discourage you from doing genetic testing?

- ☐ The doubt for the usefulness of the test result
- ☐ The cost of the genetic testing service
- ☐ The concerns about genetic information
- ☐ The reliability of the result
- ☐ The potential return of unwanted information

Q17 . What are the actions you are going to take after having your gene tested?

- ☐ Increase my control over my health
- ☐ Stimulate discussion about personal health within families
- ☐ Influence my future health care decisions
- ☐ Consult a physician
- ☐ Modify my lifestyle if risk genes diagnosed
- ☐ Do nothing

Q18 . As far as you know, does the government regulate genetic testing, or not?

- ○ Yes
- ○ No
- ○ Don't know

Q19 . Do you think the government SHOULD regulate genetic testing, or not?

- ○ Yes
- ○ No

Don't know

Section C - The impact of genetic technologies on women

Q20 . As far as you know, is it scientifically possible today to use genetic testing during PREGNANCY to find out whether the baby will develop a disease such as sickle cell disease or cystic fibrosis?

Yes

No

Don't know

Q21 . As far as you know, is it scientifically possible today to change a baby's genetic make-up before it is born so it is smarter, stronger, or better looking?

Yes

No

Don't know

Q22 . Have you or has anyone you know well ever thought to become pregnant by using the process of in vitro fertilization? (In vitro fertilization is the process where eggs are removed from a woman's ovaries, fertilized in the laboratory with sperm, then implanted in a woman's womb, where they grow and are born like other babies.)

Yes

No

Don't know

Q23 . (READ IF FEMALE) On May 14, 2013, Angelina Jolie was diagnosed with a fatal gene, BRCA1, which sharply increased her risk of developing breast cancer and ovarian cancer. As a result, she decided to do a double mastectomy (the surgical removal of one or both breasts, partially or completely, to eliminate breast cancer tissue). If your genetic testing showed that you were carrying the BRCA1 or BRCA2 mutations which may cause you breast cancer, would you conduct (double)

mastectomy operations as Angelina Jolie did to prevent the risk of having breast cancer?

- Yes
- No
- Don't know

Q24 . As far as you know, does the government regulate mastectomy, or not?

- Yes
- No
- Don't know

Q25 . Do you think the government should regulate mastectomy, or not?

- Yes
- No
- Don't know

Section D - Healthcare system implications

Q26 . Do you consider the genetic test result as a medical diagnosis?

- Yes
- No
- Don't know

Q27 . Who would you ask to interpret the genetic test result for you?

- I have enough knowledge about genetics to understand the results
- I would ask the genetic testing services to interpret the results

- I would ask the physicians to interpret the results
- I would not do anything with the results

Q28 . Should the physician interpret your genetic test results for you?

- Yes, because physicians have enough knowledge to interpret the results
- Yes, because physicians have a professional obligation to help individuals understand the results
- No

Section E - Privacy concerns about genetic information such as access, control and trust

Q29 . To what extent would you agree or disagree with the ethical and legal statements about genetic information below?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
We should be concerned about the privacy of our genetic information :					
We should allow our genetic information to be stored in biobanks for research purposes :					
We should allow researchers to share our personal information or personal identity with our genetic samples with the public :					
Laws/policies/rules governing the protection of our genetic information should be stricter than for other forms of personal information :					

Q30 . How much do you trust each of the following to have access to your genetic test results?

	None	A little	Some	A lot

Your doctor/physician :				
Your family members :				
Researchers funded by private sector or by industry :				
Researchers from public hospitals or universities :				
Law enforcement :				
Your health insurer :				
Your employer :				

Section F - Ethical implications of genetic testing

Q31 . To what extent would you support or oppose the uses of genetic testing under each of these scenarios?

	Strongly oppose	Oppose	Neutral	Support	Strongly support
Researchers, to find new ways to diagnose, prevent or treat diseases :					
Doctors/physicians, to identify a person's risk of having a bad reaction to a particular medicine :					
Doctors/physicians, to identify a person's risk of having a child with a serious genetic disease :					
Parents, to design their unborn babies with all desirable traits such as high intelligence or strength :					
Doctors/physicians, to identify a person's risk of a disease where no treatment or					

medication exist :					
Employers, to make decisions about hiring or promotion :					
Health insurance companies, to determine whom to insure or how much to charge :					

Q32 . On a scale of 1 to 5 (1=Completely unethical, 5=Completely Ethical), how would you feel about each situation below?

	1	2	3	4	5
Employers request genetic profiles from prospective employees before deciding to hire them or not :					
Health insurance companies require genetic information before deciding on the cost of health coverage :					
Researchers use our genetic information in their research study without our informed consent :					
Patent law can be applied to human genetic material, which means we can buy a patent for our genetic material :					

APPENDIX B
Additional data analysis

Table 1: Cross tabulation between Political View and Should government regulate genetic testing?

Political View * Should the government regulate genetic testing? Crosstabulation

			Should the government regulate genetic testing?			
			Don't know	No	Yes	Total
Political View	Conservative Part of Canada	Count	3	1	7	11
		% within Political View	27.3%	9.1%	63.6%	100.0%
		% within Should the government regulate genetic testing?	11.5%	6.7%	11.9%	11.0%
		% of Total	3.0%	1.0%	7.0%	11.0%
	Don't know	Count	10	9	15	34
		% within Political View	29.4%	26.5%	44.1%	100.0%
		% within Should the government regulate genetic testing?	38.5%	60.0%	25.4%	34.0%
		% of Total	10.0%	9.0%	15.0%	34.0%
	Green Party of Canada	Count	2	1	3	6
		% within Political View	33.3%	16.7%	50.0%	100.0%
		% within Should the government regulate genetic testing?	7.7%	6.7%	5.1%	6.0%
		% of Total	2.0%	1.0%	3.0%	6.0%
	Liberal Party of Canada	Count	3	2	9	14
		% within Political View	21.4%	14.3%	64.3%	100.0%
		% within Should the government regulate genetic testing?	11.5%	13.3%	15.3%	14.0%
		% of Total	3.0%	2.0%	9.0%	14.0%

	New Democratic Party	Count	8	2	25	35
		% within Political View	22.9%	5.7%	71.4%	100.0%
		% within Should the government regulate genetic testing?	30.8%	13.3%	42.4%	35.0%
		% of Total	8.0%	2.0%	25.0%	35.0%
Total		Count	26	15	59	100
		% within Political View	26.0%	15.0%	59.0%	100.0%
		% within Should the government regulate genetic testing?	100.0%	100.0%	100.0%	100.0%
		% of Total	26.0%	15.0%	59.0%	100.0%

Table 2: Cross tabulation between Political View and Should the government regulate genetic technologies?

Political View * Should the government regulate genetic technologies? Crosstabulation

			Should the government regulate genetic technologies?			
			Don't know	No	Yes	Total
Political View	Conservative Part of Canada	Count	4	2	5	11
		% within Political View	36.4%	18.2%	45.5%	100.0%
		% within Should the government regulate genetic technologies?	12.9%	14.3%	9.1%	11.0%
		% of Total	4.0%	2.0%	5.0%	11.0%
	Don't know	Count	13	6	15	34
		% within Political View	38.2%	17.6%	44.1%	100.0%
		% within Should the government regulate genetic technologies?	41.9%	42.9%	27.3%	34.0%
		% of Total	13.0%	6.0%	15.0%	34.0%
	Green Party of Canada	Count	2	1	3	6
		% within Political View	33.3%	16.7%	50.0%	100.0%
		% within Should the government regulate genetic technologies?	6.5%	7.1%	5.5%	6.0%
		% of Total	2.0%	1.0%	3.0%	6.0%
	Liberal Party of Canada	Count	5	2	7	14
		% within Political View	35.7%	14.3%	50.0%	100.0%
		% within Should the government regulate genetic technologies?	16.1%	14.3%	12.7%	14.0%
		% of Total	5.0%	2.0%	7.0%	14.0%
	New Democratic	Count	7	3	25	35

	Party	% within Political View	20.0%	8.6%	71.4%	100.0%
		% within Should the government regulate genetic technologies?	22.6%	21.4%	45.5%	35.0%
		% of Total	7.0%	3.0%	25.0%	35.0%
Total		Count	31	14	55	100
		% within Political View	31.0%	14.0%	55.0%	100.0%
		% within Should the government regulate genetic technologies?	100.0%	100.0%	100.0%	100.0%
		% of Total	31.0%	14.0%	55.0%	100.0%

Table 3: Cross tabulation between Political View and Should genetic law be stricter than other forms of personal information?

Political View * Genetic law stricter Crosstabulation

			Genetic law stricter					
			Agree	Disagree	Neutral	Strongly agree	Strongly disagree	Total
Political View	Conservative Part of Canada	Count	2	0	4	5	0	11
		% within Political View	18.2%	0.0%	36.4%	45.5%	0.0%	100.0%
		% within Genetic law stricter	5.7%	0.0%	12.9%	20.8%	0.0%	11.0%
		% of Total	2.0%	0.0%	4.0%	5.0%	0.0%	11.0%
	Don't know	Count	12	3	13	6	0	34
		% within Political View	35.3%	8.8%	38.2%	17.6%	0.0%	100.0%
		% within Genetic law stricter	34.3%	37.5%	41.9%	25.0%	0.0%	34.0%
		% of Total	12.0%	3.0%	13.0%	6.0%	0.0%	34.0%
	Green Party of Canada	Count	3	1	1	1	0	6
		% within Political View	50.0%	16.7%	16.7%	16.7%	0.0%	100.0%
		% within Genetic law stricter	8.6%	12.5%	3.2%	4.2%	0.0%	6.0%
		% of Total	3.0%	1.0%	1.0%	1.0%	0.0%	6.0%
	Liberal Party of Canada	Count	5	1	3	4	1	14
		% within Political View	35.7%	7.1%	21.4%	28.6%	7.1%	100.0%
		% within Genetic law stricter	14.3%	12.5%	9.7%	16.7%	50.0%	14.0%
		% of Total	5.0%	1.0%	3.0%	4.0%	1.0%	14.0%
	New Democratic Party	Count	13	3	10	8	1	35
		% within Political View	37.1%	8.6%	28.6%	22.9%	2.9%	100.0%
		% within Genetic law stricter	37.1%	37.5%	32.3%	33.3%	50.0%	35.0%
		% of Total	13.0%	3.0%	10.0%	8.0%	1.0%	35.0%
Total		Count	35	8	31	24	2	100
		% within Political View	35.0%	8.0%	31.0%	24.0%	2.0%	100.0%

	% within Genetic law stricter	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
	% of Total	35.0%	8.0%	31.0%	24.0%	2.0%	100.0%

Table 4: Cross tabulation between the awareness of Angelina event and the opinion on double mastectomy

Angelina Jolie * Double Masectomy Crosstabulation

			Double Masectomy			
			Don't know	No	Yes	Total
Angelina Jolie	Don't know	Count	1	0	0	1
		% within Angelina Jolie	100.0%	0.0%	0.0%	100.0%
		% within Double Masectomy	2.4%	0.0%	0.0%	1.0%
		% of Total	1.0%	0.0%	0.0%	1.0%
	No	Count	9	7	6	22
		% within Angelina Jolie	40.9%	31.8%	27.3%	100.0%
		% within Double Masectomy	22.0%	35.0%	15.4%	22.0%
		% of Total	9.0%	7.0%	6.0%	22.0%
	Yes	Count	31	13	33	77
		% within Angelina Jolie	40.3%	16.9%	42.9%	100.0%
		% within Double Masectomy	75.6%	65.0%	84.6%	77.0%
		% of Total	31.0%	13.0%	33.0%	77.0%
Total		Count	41	20	39	100
		% within Angelina Jolie	41.0%	20.0%	39.0%	100.0%
		% within Double Masectomy	100.0%	100.0%	100.0%	100.0%
		% of Total	41.0%	20.0%	39.0%	100.0%

Table 5: Cross tabulation between age and the level of concern about the genetic information concern

Age * Genetic information privacy concern Crosstabulation

			Genetic information privacy concern					
			Agree	Disagree	Neutral	Strongly agree	Strongly disagree	Total
Age	18-20	Count	3	1	3	3	1	11
		% within Age	27.3%	9.1%	27.3%	27.3%	9.1%	100.0%
		% within Genetic information privacy concern	8.3%	33.3%	20.0%	6.8%	50.0%	11.0%
		% of Total	3.0%	1.0%	3.0%	3.0%	1.0%	11.0%
	21-24	Count	18	0	5	16	1	40
		% within Age	45.0%	0.0%	12.5%	40.0%	2.5%	100.0%
		% within Genetic information privacy concern	50.0%	0.0%	33.3%	36.4%	50.0%	40.0%
		% of Total	18.0%	0.0%	5.0%	16.0%	1.0%	40.0%
	25-29	Count	7	2	3	10	0	22
		% within Age	31.8%	9.1%	13.6%	45.5%	0.0%	100.0%
		% within Genetic information privacy concern	19.4%	66.7%	20.0%	22.7%	0.0%	22.0%
		% of Total	7.0%	2.0%	3.0%	10.0%	0.0%	22.0%
	30-40	Count	4	0	3	8	0	15
		% within Age	26.7%	0.0%	20.0%	53.3%	0.0%	100.0%
		% within Genetic information privacy concern	11.1%	0.0%	20.0%	18.2%	0.0%	15.0%
		% of Total	4.0%	0.0%	3.0%	8.0%	0.0%	15.0%
	40-50	Count	2	0	1	1	0	4
		% within Age	50.0%	0.0%	25.0%	25.0%	0.0%	100.0%
		% within Genetic information privacy concern	5.6%	0.0%	6.7%	2.3%	0.0%	4.0%
		% of Total	2.0%	0.0%	1.0%	1.0%	0.0%	4.0%
	50 and above	Count	2	0	0	6	0	8
		% within Age	25.0%	0.0%	0.0%	75.0%	0.0%	100.0%

	% within Genetic information privacy concern	5.6%	0.0%	0.0%	13.6%	0.0%	8.0%
	% of Total	2.0%	0.0%	0.0%	6.0%	0.0%	8.0%
Total	Count	36	3	15	44	2	100
	% within Age	36.0%	3.0%	15.0%	44.0%	2.0%	100.0%
	% within Genetic information privacy concern	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
	% of Total	36.0%	3.0%	15.0%	44.0%	2.0%	100.0%

Table 6: Cross tabulation between Gender and the opinions on designing babies

Gender * Design babies Crosstabulation

			Design babies					
			Neutral	Oppose	Strongly oppose	Strongly support	Support	Total
Gender	Female	Count	7	14	33	1	7	62
		% within Gender	11.3%	22.6%	53.2%	1.6%	11.3%	100.0%
		% within Design babies	43.8%	58.3%	70.2%	33.3%	70.0%	62.0%
	Male	Count	9	10	13	2	3	37
		% within Gender	24.3%	27.0%	35.1%	5.4%	8.1%	100.0%
		% within Design babies	56.3%	41.7%	27.7%	66.7%	30.0%	37.0%
	Other	Count	0	0	1	0	0	1
		% within Gender	0.0%	0.0%	100.0%	0.0%	0.0%	100.0%
		% within Design babies	0.0%	0.0%	2.1%	0.0%	0.0%	1.0%
Total		Count	16	24	47	3	10	100
		% within Gender	16.0%	24.0%	47.0%	3.0%	10.0%	100.0%
		% within Design babies	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%