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# Jordanian Ethical Perceptions of Preimplantation Genetic Diagnosis

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## Abstract

Preimplantation Genetic Diagnosis (PGD) is a procedure that can be done during In Vitro Fertilization (IVF), involving genetic and chromosomal screening of fertilized embryos prior to implantation into a woman’s uterus. After PGD, only the embryos possessing the desired characteristics are implanted, while the other embryos are frozen for future use, or discarded. PGD is used for family balancing (gender selection for balancing the gender dynamic within a family), gender selection to screen out sex-linked diseases, or a broader genetic screening for diseases known to be present in the patient’s family history.

Many ethical questions have been raised about PGD, especially in its use for family balancing. The root of ethical views may be linked to culture, religion, or social tradition. It is the goal of this research to understand the ethical views of Jordanian medical professionals involved in PGD regarding the practice through in-depth interviews, and to explore the opinions of the general public regarding PGD in order to gain a broader understanding of Jordanian ethical perceptions behind PGD. Do medical professionals see PGD as ethical? What is the spectrum of this? Do young adults have opinions about family balancing, genetic screening, and their legality? These answers are needed to further understand ethics of PGD, where they are derived from, and what the future of the procedures may look like.

The findings of this study highlight the complexity behind the roots and ethics of PGD. The significance of this study lies in its analysis of opinions in Jordan, a country without legal restrictions of PGD. Because many countries do not consider some, if not all, aspects of PGD legal, it is necessary to understand the perceptions of those who are working and living in Jordan. Only by further understanding the root ethics behind beliefs regarding PGD will analysis of issues be possible.

## Introduction

Preimplantation Genetic Diagnosis (PGD) is a process by which embryos fertilized using In Vitro Fertilization (IVF) can undergo genetic screening prior to implantation in the patient's uterus (Human Fertilisation & Embryology Authority, 2013). The genetic screening reveals the fertilized embryo's gender, as well as any genetic make-up, allowing mutations that cause genetic diseases to be noted. Screening for genetic diseases enables families to decrease the likelihood that their child will carry on the genetic disease. Some of these genetic diseases correlate to specific genders, which is one basis for gender selection. The other reason that gender selection is employed is for gender balancing in families. Family balancing is the practice of actively implanting only embryos of one sex, in order to balance out the family gender dynamic. Generally, it is only used if a family already has several children of one gender, and therefore wants the opposite gender (Human Fertilisation & Embryology Authority, 2013).

These procedures are a part of Assistive Reproductive Technology (ART), and are offered in some Jordanian In Vitro Fertilization (IVF) clinics. According to a lecture that the Jordan: Health and Community Development program attended at The Specialty Hospital of Amman, PGD services are a part of the medical tourism industry, in which Jordan partakes (Dr. Fawzi Hammouri, personal communication, Fall, 2013). Some countries do not allow PGD to be used at all, or have limitations for what circumstances allow it to be offered. Jordan, however, does not have restrictions or any regulations for PGD use, and due to its relatively inexpensive prices, and ease of access and navigation, Jordan has become a destination for patients seeking PGD from the region, and the world (Dr. Fawzi Hammouri, personal communication, Fall, 2013).

The legal freedom that Jordan offers in terms of PGD is somewhat unexpected due to its conservative and religious social and cultural structure. The source of this freedom is curious, and worth further study. The legal code in Jordan is based on a strict religious code, which does not seems to support interfering with natural selection of gender. So, why has PGD remained legal?

Once research on PGD is initiated, the complexity of the ethics behind it may become clear. International attention has been raised regarding this issue; medical, legal, and religious communities have addressed it (Vatanoglu and Elif, 2012). Consensus between these groups about PGD provision has not been reached, which further peaks interest and inspires research. Because Jordan does not restrict PGD use, and as it is a growing economic hub where religion continues to affect both the culture and legal system, it acts as an ideal place to study the ethics behind PGD.

Emine Lutz (2012) addresses the legal issues of genetic screening. With current legal regulation, individuals are often allowed to assess the morality of PGD for themselves, in regards to their beliefs and values. New developments continue to occur, and with each new process, scientists and doctors must decide what should be available to the public. Some countries, such as Germany, have banned embryo testing altogether, while some (e.g. Britain, Spain) have limited it to certain circumstances. Legal issues are a direct effect of ethical issues, and a non-unanimous opinion on them should be cause for concern. Lutz presents his ideas from an objective position, stating each argument and consequence without providing personal viewpoints (Lutz, 2012).

Bioethics is a constantly developing field, which correlates to the expansion of medical technology and available medical procedures. Its interloping connection with medicine makes it a relevant topic to Jordan: Health and Community Development. Health study is not just about the physical and mental well being of a society; it involves the cultural background, system infrastructure, and medical developments. Gender selection and genetic screening relate to all of this, and is an integral part of reproductive health that is rapidly developing not only in Jordan, but also on an international scale.

Heidi Malm (2012) presents one bioethical point of view in her analysis of moral duty in PGD. Malm cannot understand how choosing the advantaged embryo through PGD is morally acceptable, as it ignores the other fertilized embryos. She outlines her opponents' arguments, (such that PGD medically benefits society, eliminates suffering, etc). After each point, she counters with her own views, which involve right to life and financial burdens. Malm fights the notion that genetic screening is a moral duty, as it disregards the life of some fertilized embryos in an attempt to have a more perfect child (Malm, 2012).

The ethical consideration of PGD is a very broad topic. In order to make this research feasible with a three-week timeline, focus is narrowed to the ethical perceptions of PGD, as seen by medical professionals involved in PGD. This population has both the exposure and experience in dealing with the ethical considerations of gender selection and genetic screening that makes them a viable interviewee group. As medical professionals, some of the topic sensitivity is lessened, and conversation made more open.

For the survey component of this research project, the target population switched from patients in IVF clinics to young adults aged 20-30. Permission to survey patients was not granted, and so an alternative survey population generated. This new survey measures the opinions of young adults regarding the ethics of gender selection, genetic screening, and legal regulation of the two procedures. These opinions are important to collect, as it is this population who will be deciding on policy and limits for the development of PGD in the next few decades.

In the design of this research project, there is a main assumption that the medical professionals who are involved in PGD will have a perspective on the ethics behind Preimplantation Genetic Diagnosis. It is hypothesized that the medical professionals who offer PGD services will find it ethical for gender selection and genetic screening, under specific circumstances. There will be a perceived limit to when PGD should and should not be used. Additionally, it is hypothesized that the population surveyed will have varying opinions regarding the ethics of gender selection, genetic screening, and regulating these procedures, based on their gender.

The control variable for interviewees is that all participants are medical doctors who offer PGD services. The control in the survey group is that all are young adults aged 20-30. The independent variable measured in the interviews is the presence of perspective on the ethics behind PGD. The dependent variable measured in the interviews is the ethical perception of PGD, and any perceived limits to the service. The variables measured in the patient survey are gender, religion, nationality, educational attainment, marital status, and the opinions on whether gender selection, genetic screening, and regulating these procedures are ethical.

The ethical considerations regarding Preimplantation Genetic Diagnosis (PGD) involve finding a line when Assistive Reproductive Technology (ART) should be permissible, and when it should not be. Published papers from the past two decades discuss this issue, suggesting a variety of purposes that the procedure should serve. This research paper is based on the general theory that ART is permissible for some, but not all cases. Additionally, this research explores the various bases for moral theory behind limiting and allowing gender selection and genetic screening.

## Literature Review

As a medical procedure, Preimplantation Genetic Diagnosis (PGD), and its regulation and legality, can be viewed in the context of bioethics. Gender selection and embryonic genetic screening may be argued as ethical or not, or conditionally so, as derived from a number of angles. Religious reasoning underlies some arguments, but others are based on alternative moral systems. Michael Moreland authors an article on the moral reasoning in bioethics, and claims that bioethics today has developed from both moral philosophy and moral theology (Moreland, 2009). Whether base ideologies are philosophical or theological, there may be stark differences within or between each branch. As an example, Moreland cites both Immanuel Kant and John Stuart Mill's philosophies on morality: utilitarian and deontological ideals. Analyzing the ethical arguments of PGD in context of Kant and Mill will demonstrate how complicated the moral debate has become.

John Stuart Mill's moral theory is utilitarianism. Essentially, this doctrine involves deeming an action morally acceptable based on its happiness effect. This is explained in Mill's work *Utilitarianism*: "'…actions are in the right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness…'[II 2;cf.II]" (Brink, 2008). This is merely a fragment of Mill's larger theory, and he goes on to provide thorough explanations and spectrums of morality. For example, 'higher pleasures' are explained through the idea of hedonism, where the mental state of pleasure is the only thing that has true meaning. External, or extrinsic, pleasure (including that which is caused by action or activity) can only be measured in moral value by to what extent it causes mental pleasure, or intrinsic value. Therefore, the intrinsic can be affected by the extrinsic, but no matter the motivating factor, its moral value is dependent on how much happiness it may cause. This happiness is not just personal – ‘greatest happiness’ depends on the number of people feeling a large quantity of pleasure (Brink, 2008).

Immanuel Kant’s moral theory is based on duty. Right and wrong, for Kant, depends not on the effect, but on the motivation (Gaskill, 2008). As seen by Kant, moral duty is a universal concept, where actions are measured by whether they can be expected from the general populous, as well as if they “respect the goals of human beings,” and not used purely for personal purpose. This means that an action may be deemed morally acceptable if the motivation is just, regardless of whether the result causes pleasure. Kant believes that motivation derives from a source that has universal prevalence. Actions can only be considered right if the doer can expect the same action from anyone put in their situation (Gaskill, 2008).

Simplified, Mill measures morals based on outcome, while Kant does so on motivation. Although these two ideas do not immediately appear to compliment each other, a closer analysis must be made. According to the ideas presented Michael Moreland, there is no universal reasoning. However, this does not mean that different philosophical and theological traditions do not “share some notions that may be of help in resolving moral disputes (Moreland, 2009).” So, as seen by the researcher, when deciding if gender selection is acceptable, an individual may use the Kantian view: motivation for selecting (for example) a male embryo is a decision that may be expected from any parent, within a particular circumstance. Choosing to have a boy may be viewed as a moral duty, in order to create the opportunity for greater happiness. This greater happiness, though, is also a utilitarian goal, and thus can also be supported by Mill’s moral theory.

The opposite result of reconciling Mill and Kant can occur. Selecting a male embryo for selfish reasons (e.g. personal desire to have an additional male figure in the family) may not be viewed as a duty expected from the universal population. Additionally, it may not create the greatest happiness possible, as it disregards the potential happiness of any other fertilized embryos. It also disregards a potential societal need for more women, should male selection outnumber female selection. So, in this context, gender selection satisfies neither Kant nor Mill's theory of morality. This demonstrates that the two differing moral theories may be merged to support more than one perception of gender selection. Consequently, the legal and ethical debates of PGD become subjective and circular.

Thomas Csordas' article "Morality as a Cultural System?" (2013) may be utilized to view PGD under a cultural scope, and in doing so, contrast the analysis that uses Moreland's theory. Csordas cites several different works in order to present morality in an anthropological framework. He presents Didier Fassin's idea that morality "should be treated as a social domain just as are religion, politics, or medicine," and is thus a cultural phenomenon. Another approach addressed by Csordas comes from Arthur Kleinman and Steven Parish, which states, "morality is a form of consciousness, the seat of which is the self embedded in the context of a collective moral sensibility" (Csordas, 524). According to the researcher, 'collective moral sensibility' may be derived from societal aspects such as religion, legal framework, and cultural history. These three facets of a society will not generally match up to another society, let alone the global society. If this is the case, then how can an agreement on the ethics of something like PGD be established? Without agreement, it becomes nearly impossible for a universal regulation of the procedure to occur. This particular issue attracts much attention from the international medical community, and has been addressed by a variety of angles, as presented by this literature review.

Isaac Rabino (2003) discusses some concerns of Preimplantation Genetic Diagnosis, within the scope of the opinions presented by professionals involved in the Human Genome Project (HGP). The HGP acknowledged early in its development that psychosocial, ethical, and legal issues would arise with the expansion of PGD and other genetic screening. These issues do not solely apply to those involved in PGD, but to society as a whole. Professionals from medical, religious, and political backgrounds will need to continually address the issues, lest it remain unregulated. Without regulation, moral and ethical implications of genetic manipulation will begin to affect power structures. Rabino's study specifically addresses what the limits to genetic screening should be: which genes should be screened for, and which should not be. His results are varied, demonstrating that the professionals involved in the HGP do not share the same opinions regarding limits to their work. The differences that exist split at the line of life improvement being at the absence of disease, versus the enhancement of genetic make-up. Basically, physical attributes that relate to disability and physical attributes that relate to attraction becomes the chasm in genetic screening. However, even within the attributes that cause disability, there is debate as to what should count as a disability (Rabino, 2003).

As understood by the researcher, Rabino's results can be brought back to Kant and Mill. Genetic screening for diseases may be viewed as human duty, as it may improve the future child's quality of life. Additionally, elimination of genetic disabilities will decrease societal burden, as care for the individuals will no longer be a relevant issue. The elimination of disability also eliminates a large amount of pain, which ties into the Utilitarian doctrine. Countering this, however, is the notion that not everyone can be expected to make the decision that genetic screening is his or her moral duty. Perhaps a 'right to life' opinion overrides the desire to ensure a disability-free child. The argument for preventing disease and disability can be considered selfish, and not in the best interest of societal happiness. Therefore, society may benefit from the presence of disability and disease: it creates a job market, as well as inspires empathy (to address the issue from both a practical and emotional front).

Peter Braude and Frances Flinter (2007) further discuss the possible uses of Preimplantation Genetic Diagnosis (PGD). The procedure was first developed in order to try to decrease the prevalence of passing on genetic mutations that cause disease and disability. The initial condition being screened for was mental retardation. As the science and technology behind PGD has developed, the success rate has increased, but it remains inconsistent. Success may vary depending on the gene being screened for, as well as the number of embryos harvested for screening. Besides success rates, another obstacle towards the success of PGD is the cost. Public funding for research is minimal, and financial support of aid-dependent patients is either minimal or nonexistent, depending on the society. Because of these challenges, Braude and Flinter imply that use of PGD should be more closely monitored, especially since the technology is on the brink of taking off. They maintain that any testing done needs to be medically justified (Braude and Flinter, 2007).

In agreement with Braude and Flinter, Wolfram Henn (2000) notes that genetic screening must only be used for cases in which the conditions are deemed incurable. Henn fears the development of perceptions that would support the employment of PGD for reasons other than medically benefitting the future child. Concern that the whole process will be adopted by consumerist attitudes drives Henn to encourage regulation of genetic screening. Henn believes that the World Health Organization should create guidelines regarding the ethical acceptability of human genetic testing. With a broad universal ruling, limits to what may be done with genetic screening will be in place throughout the world. Henn believes that, if left unchecked, genetic screening will expand out of control, and will be subject to too many differing moral guides (Henn, 2000).

As is evident, there are a number of opinions regarding PGD, and its ethical implications. Because there are so many different fundamental beliefs, the arguments for and against gender selection, genetic screening, and the regulation of each extend in many directions. With all of the differing approaches to address the issue, identifying one root for the ethics behind PGD procedures does not seem likely. As with the ethics of any matter, reasoning varies with culture, religion, societal tradition, as well as all other demographic elements. While attempting to identify the base of this thinking may help the theoretical understanding of issues, it does not seem to aid in finding consensus for policy purposes.

Prior to this research project, there had been no evident studies done in Jordan that involve perceptions on PGD and the ethics behind it. Only by further research will the issue be better understood, and understanding is a prerequisite to developments in policies to regulate PGD.

## Methodology

### *Design*

The purpose of this study is to measure the ethical perspectives regarding Preimplantation Genetic Diagnosis (PGD), as seen by Jordanian medical professionals who offer PGD services. Additionally, the public opinion of young adults, aged 20-30, was sought in order to further understand the Jordanian opinion on the ethics of PGD.

This research was of mixed method. Both qualitative (interviews) and quantitative (surveys) data was collected. The sample was obtained using convenience and purposive methods, with 5 medical doctors as interviewees, and 50 survey participants. Convenience and purposive sampling was used in order to access the particular medical professionals and the target population of interest. The interview involved broad questions to gauge the ethical opinions regarding PGD, as well as to understand the root of these beliefs. For surveying, the age group 20-30 was chosen, as this is the population who will be voting on and deciding policy of PGD and its developments in the future. Because doctors interviewed all expressed anticipation of the future developments and capabilities of PGD, understanding the perspective of this age group is key in order to gauge how PGD policy may develop with its technology. The survey involved ten questions, six demographic-based, and four about ethical opinions regarding PGD. For the questions that asked if an aspect of PGD was ethical, the possible answers were "yes," "no," or "no opinion."

Because of the researcher's connections and living situation in Amman, this city served as the setting for all research. Amman is an appropriate choice, as it is the capital of Jordan, and so has a large medical system that includes clinics that offer PGD.

Interviewing was selected as an appropriate method of gaining medical professionals' perception, as it allows in depth and probing questions to be asked. Surveys were selected as an appropriate tool for accessing the target population's opinions, as it provided adequate but simple quantitative data needed for a more comprehensive analysis of opinions on PGD ethics.

The population interviewed and surveyed was limited by the purposive decision to only offer them in English. This decision was made due to the short research period and lack of fluency in Arabic. Adding Arabic versions of either would have required more human resources than were easily available. Keeping everything in English, and utilizing the English speaking population helped eliminate a lot of possible misunderstanding. However, most medical professionals working in Jordan are fluent in English, so the interviews were not really limited by the language barrier. Recognizing the limitations that language implements on this research, as well as that of abbreviated research time, suggests research integrity.

Overall, researching the ethics behind Preimplantation Genetic Diagnosis (PGD) in Jordan created challenges, demanded patience, and offered valuable insight into the subject. Having to establish contacts and find willing interviewees meant practicing multi-lingual communications, as well as overcoming any social inhibitions. Sitting in the waiting rooms of IVF clinics provided time to observe and reflect. Introducing the research to doctors required eloquence and persistence – not all were welcoming and willing to participate. Surveying became even more of a problem, as clinics were not willing to allow their patients to be surveyed. Because of this, the original aim for the survey population switched to a larger, more general group: 20-30 year olds.

This research project, however brief, was an important experience, as it demanded strict adherence to the research process, and demonstrated how research, no matter how pre-calculated, must sometimes be altered at a moment's notice.

### *Data Collection*

1. A general list of Amman's IVF clinics that offer Preimplantation Genetic Diagnosis (PGD) services was derived through an Internet search. All clinics yielded in this search were emailed about potential participation in the research project. One clinic responded negatively.

2. Next, all clinics were phoned, in order to gauge interest in participation through a second means of communication. Appointments with two clinics were scheduled, and one clinic requested appointments be made in person. No other clinic receptionists understood English well enough to be of assistance.

3. The appointments scheduled by phone turned out to be for a potential patient. This misunderstanding was cleared at the appointment time, and interviews were conducted. At the clinic that requested appointments to be made in person, the Director ended up refusing an interview, and forbid research to be conducted in his clinic. This will later be expanded on further.

4. The other clinics were visited without a prior appointment. Upon arrival, the research subject was explained to the receptionist, and a request to see the head doctor was made. This resulted in one more interview. The final two interviews were scheduled through the academic director of the Jordan: Health and Community Development program. Perhaps this demonstrates the importance of personal connections.

5. After interviews were conducted, the recordings were transcribed, to better enable a thorough analysis of the perceptions regarding the ethics behind PGD.

6. For the revised survey method, public distribution involved approaching people who appeared to be in the targeted age group, as well as requesting the participation of some classmates and other acquaintances. This method is appropriate due to the convenience and purposive nature of the sampling technique. When approached, subjects were asked if they spoke English, and if the answer was affirmative, an introduction of the research was given. Finally, their voluntary participation was requested. If consented, the subjects would complete the survey, then hand it back.

7. Following all data collection, analysis commenced. This involved descriptive statistics for the survey, and a general analytical procedure for the interviews. As all interviewee information is anonymous and confidential, the locations of the clinics may not be revealed.

The ethical considerations of this study mandated that all interviews had prior written, informed consent. All surveys had general consent given by voluntary participation in filling them out. Additionally, no research was done prior to approval from the Local Review Board, and changes were also approved before implementation. All recordings were deleted after transcriptions, and with that, any identifying data of the participants.

### *Obstacles*

Two major obstacles were faced during the research process. The refusal of doctors to sit for an interview was an unanticipated issue, because confidentiality and anonymity were to be maintained. One of the doctors who refused an interview instead offered a long explanation as to why research on ethics behind PGD, and specifically gender selection, in the Middle East is inappropriate. He warned against pursuing it, suggesting that the topic brings up sensitive material that people would be unwilling to discuss with a Western woman. The sensitivity made it a "dangerous" topic, as it brings up culture, religion, and societal norms that a Westerner may not be able to appreciate or comprehend. This direct and strong opinion was, although unhelpful to the official research, important to hear. It indicates that even in a professional setting, some people cannot disassociate emotion from academic material – no matter how important it is to discuss.

The second major obstacle was in not obtaining clinic approval to survey patients. Instead of detracting from the research, however, this setback in some ways improved the project. After re-evaluating the research progress, and reviewing what was being learned from interviews, it was realized that the future of policy regarding PGD might be just as important as present opinions. All interviewees suggested some type of excitement, but apprehension about the developing PGD technology. There is no denying that science makes more and more possible everyday. While some of the technology will help screen for more genetic mutations and eliminate more diseases, there may be less medically important advancements that come from advanced reproductive technology development. Policy about when PGD should and should not be used only exists in some countries. As PGD expands its possibilities, policy gains importance and relevance. It is because of this that the opinion of the 20-30 year old population must be studied. This population will be engaged in policy establishment or modification in the next few decades. This population has the potential to shape the future of PGD.

In general, the obstacles faced did not detract from the research. Valuable information was collected out of both research changes. Although the depth of this research is not impressive, it has established a base for more research to be done in the future.

## Findings

### *Interviews*

With eight questions about the ethics of Preimplantation Genetic Diagnosis (PGD), the interviews with medical professionals who perform PGD offered a variety of insight into the different perceptions that exist within one small population. The interviews spanned seven definite themes: possible procedures done through PGD; role of doctors in monitoring family balancing; the religious and cultural bases for why family balancing is perceived as ethical; the genetic screening aspect of PGD; the non-universal status of ethics; regulation of PGD procedures; and the need for further research. Each interview provided slightly different takes on these topics.

Of the aspects of PGD that were mentioned by all interviewees, most important was the breakdown in types of PGD. Patients seek PGD for three main reasons: family balancing (gender selection in order to have a child of a specific gender); a parent is a known carrier of a sex-linked disease (gender selection to avoid the affected gender); or screening for another type of genetic disease. Each doctor clarified that they will strongly discourage family balancing if the family has not yet attempted natural conception. This appears to be a common practice in reproductive clinics. One of the interviewed doctors works for a clinic that takes this practice one step further, and insists that a family have two of the same gender before they use PGD for selection of the opposite gender.

If it provides clinics with business, why do the doctors self-regulate the procedures they offer? This monitoring of family balancing prevents an uneven population growth between males and females, according to one doctor. A different interviewee briskly dismissed the 'commonly-held' notion that gender selection will create an imbalance of men and women. Another doctor addressed the issue by suggesting that "you cannot balance something that doesn't exist," and so family balancing must only be used in an already girl or boy-dominant family. Additionally, while Arab patients often seek sons, European patients oftentimes want girls. The researcher notes that this aligns with the heavily patriarchal society in the Arab world. Culture deems men an especially important part of society, holding male esteem higher than female. While some may dispute this fact, arguing that the culture regards women as an essential part of the family, and the most respected within the family dynamic. The researcher suggests that tying respect for women to the family, and men's respect to their place in the larger society is, in essence, still a patriarchal system.

Despite the common practice of family balancing that occurs in the clinics that the interviewees work in, only one of the doctors interviewed said they would use gender selection in their own families. Most doctors claimed satisfaction with either gender, admitting that they do not feel the need to utilize the technology. This was an unexpected contradiction between belief and practice. A female doctor interviewed claimed she values girls just as much as boys, and with audible pride talked about her daughters, insisting she does not need a son. She is so adamant about valuing girls, but is still willing to throw out XX chromosomes so that her patients may have sons instead of daughters. It seems as though she is enabling a practice that will only further society's preference for sons – one that she clearly does not agree with.

A lack of desire to utilize gender selection in their own families apparently does not mean doctors believe it to be unethical. Several ethical arguments for gender selection were cited, involving religion, culture, and social expectation. One doctor believes that in this region, religion comes before ethics, and that must be accepted. To this, the researcher points out that many people's ethics are based in religion. Additionally, the major religion in this region is Islam, and Islam celebrates the birth of daughters as well as the birth of sons (alahazrat.net, 2013). So, disposing of one gender in the goal of having the other seemingly contradicts the values of Islam.

Another doctor disassociated ethics with religion, and tied it more to culture. Although selecting sons over daughters does line up with the patriarchal culture in Jordan, religion cannot be dismissed. However, no matter the root cause, social expectation and tradition does appear connected to the ethical standard. Inheritance, family name, and future care for parents were all mentioned as social reasons to employ gender selection. These excuses for offering gender selection for family balancing appear, to the researcher, as attempts to justify a practice that they know is not entirely ethical.

According to one interviewee, the inheritance law in Jordan leaves all wealth to sons. If a family has only daughters (or no children), the inheritance goes to the father's brothers before the daughters. For this reason, it is quintessential to have a son in order to keep wealth in the immediate family. This law is based on Islamic code, and so ties into religion. However, this law does not completely disregard daughters. It still ensures that the wealth is distributed to the family members in need, as explained by another interviewee. So, the choice to have a son for the inheritance reasoning is not necessary to ensure greatest happiness of the family, as the wealth will be obtained by all anyways. Also, while moral duty might be seen as protecting the well being of family, this will be done regardless of the presence of a son. Inheritance law will satisfy Kant's morals and Islamic code whether there is a son in the family or not. Mill's utilitarian belief also does not rely on a son to distribute family wealth.

Another purpose that only a son can serve is the carrying on of a family name. Children always take the name of their father, and so, if a family has only daughters, the family name will end within one generation. The researcher offers the opinion that this reasoning is a selfish desire, and does not necessarily promote greatest happiness, nor is it a moral duty. Neither Kant, nor Mill, nor Islam particularly cares about the carrying on of a family name.

Finally, sons are believed to be able to better care for their parents in old age. A family depends on each other for financial and social support. Old age is an especially pertinent time to have a son, as it is the point when parents become more vulnerable than their children. A son will, it is assumed, be able to provide better care for parents than daughters can. As seen by the researcher, this has no ethical base, whatsoever, and so should not be used as a reason to support family balancing. It is, rather, based on a hetero-normative belief that has no factual base.

One doctor sees gender selection as a way to support the family unit. If a woman has difficulty becoming pregnant, it is often blamed on her, not her husband. For this reason, the husband may want to divorce her, and seek a wife who may be able to have his children. PGD can enable a woman to become pregnant, even when the odds are against her. The interviewee summarizes this: “we have a purpose here to make the family one family, not two families, not three families.” Because of the emphasis placed on family life in Arab culture, it is essential for families to stay together, in order not to isolate anyone. Another doctor had a slightly different take on this issue, noting that in some countries, men cannot divorce women. So, if there is a genetic disease in the woman’s family, he will not be able to find another woman without the problem. So, PGD helps the husband avoid having children with genetic diseases, and the family accruing the social problems associated with this. In the opinion of the researcher, this argument has legitimate ground in a cultural sense, but there is not strong ethical reasoning to tie to it. In the sanctity of marriage, it is the husband’s moral duty to stand by his wife, regardless of fertility issues. If approached from the utilitarian set of beliefs, reinforcing the inappropriateness of divorce ignores the greatest happiness principle, as both parties may be happier if divorce was socially accepted.

One doctor recognized that ethical considerations are variable, depending on the culture. For example, in the UK, it is legal for lesbians to receive PGD to enable fertility, but in Jordan, this is illegal. The doctor went on to explain that when there are legal restrictions, ethics no longer matter. As long as a doctor is observing “the laws and morals of the society in which [they] are working,” then the ethical implications do not become an issue.

Ethics do not necessarily cross from one culture to another – more often than not, they alter depending on the society. This is a concept that medical professionals and policy makers must understand in order to begin working in sensitive arenas. Family balancing is one of these areas. “It’s not black and white, not as simple as right and wrong.” Ethics are rarely universal, and one person cannot expect another to adhere to the same ethic-based rules. For this reason, every case must be taken individually, seen from an objective stance.

Other doctors mirrored this sentiment of looking at each case independently. Some suggested the need for an ethics committee to oversee all PGD procedures. This could be formed by a governmental body, or by representatives from all PGD clinics in a region. Other forms of regulation were suggested in the interviews, such as legal regulation. Some of the interviewees expressed a desire for stricter laws regarding PGD, especially in who can undergo gender selection for family balancing. One viewpoint was that when PGD risks outweigh the potential benefits, it should be stopped. If the doctors see ethical problems with some aspects of PGD, why has more attention not been shined on the issue? As they work closely with PGD everyday, the doctors in this field should be heading the fight to install regulations in PGD.

As gauged by the interviews, family balancing seems to be the only ethically questioned aspect of PGD. The elimination of sex-linked and other genetic diseases was discussed as an obvious choice for patients. In Arab countries, one doctor explained, genetic diseases are even more prevalent than the Western world. Due to the high prevalence of intermarriage in families, genetic diseases are passed on with a greater frequency than in some other cultures. The researcher understands the practice of PGD for the purpose of medically benefitting future generations, although believes the social and economic implications of virtually eliminating genetic diseases has not been properly analyzed. If more people start accessing PGD for medical purposes, the procedure would become cheaper, and in turn would allow even more patients to utilize the technology. The interviewees' outlooks differ on this issue; one doctor sees it as a human right and duty to access PGD, and another predicts mass use of PGD will lead to gender imbalance.

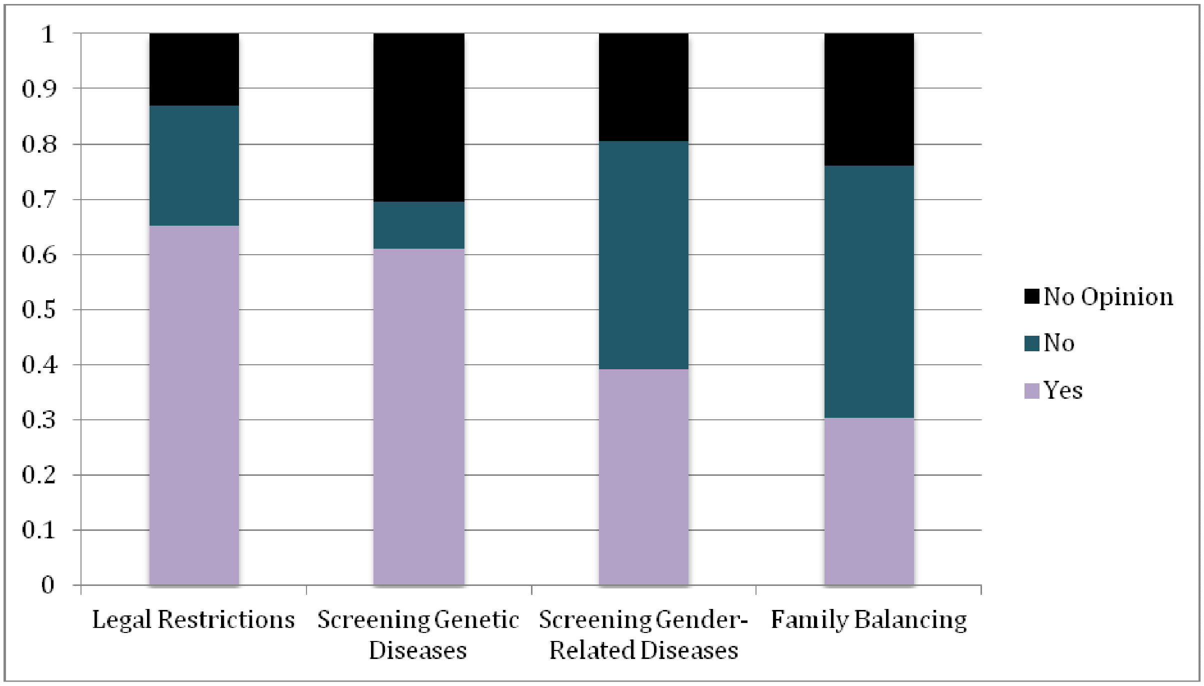
As demonstrated by this general overview of the interviews conducted, there are many differences in beliefs regarding PGD, even within the medical community. The hypothesis that medical professionals would perceive PGD as ethical, under certain circumstances is correct. The scope of circumstances varies, depending on the doctor. Additionally, there are perceived limits to PGD by the interviewed professionals. As will be discussed below, the hypothesis that the population surveyed would have varying opinions regarding the ethics of gender selection, genetic screening, and legal regulation of these procedures based on their gender, was also supported.

*Surveys*

The results obtained from the public survey meant to measure 20-30 year olds' opinions on various aspects of PGD indicate a need for additional surveying. The distribution technique involved approaching people in the public sphere of a mixed residential and commercial area in Amman, and requesting their participation in a survey regarding views on gender selection and genetic screening. Due to the time and geographic location of survey distribution, most participants were single, male, university students. Twenty-eight percent of survey participants were female, and the rest male. This creates a homogenous population. Despite this, the survey produced worthwhile results.

Because of time and resource restraints, only fifty surveys were distributed. The number was not chosen to represent a statistically significant percentage of the target population, as this would not be feasible. Of those fifty, forty-six had usable results, and four were incomplete.

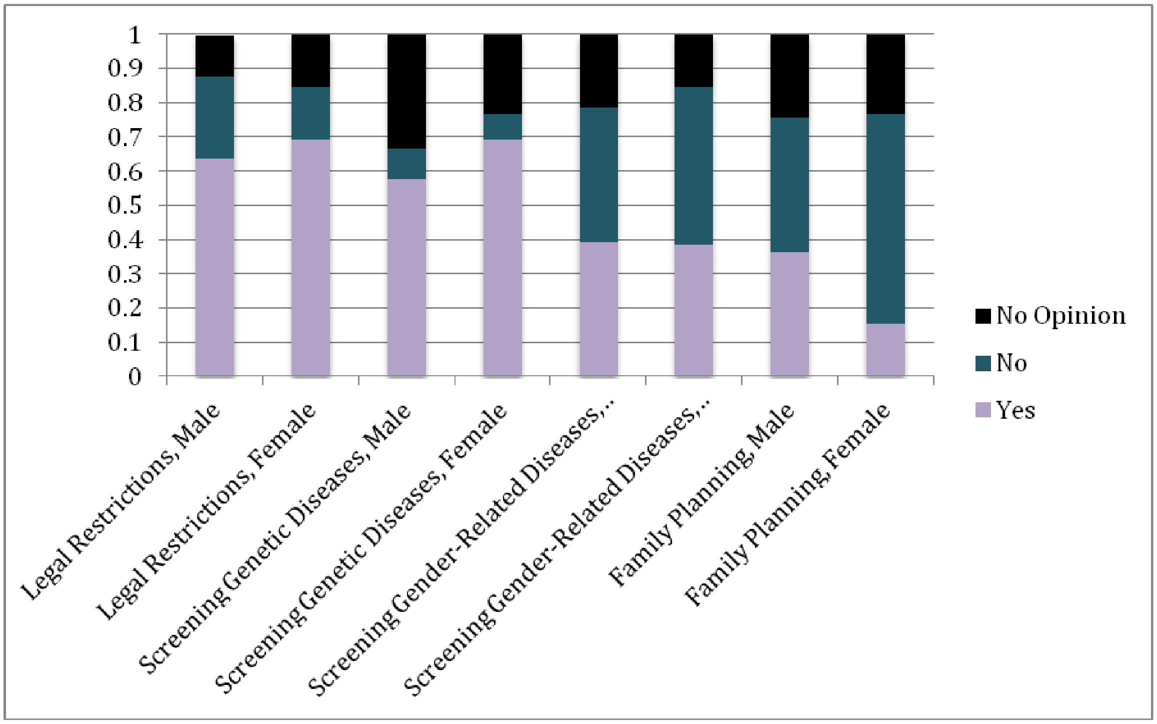
**Figure 1: Is it ethical, without breakdown**



The figure above is broken down into columns that represent each opinion-based question asked on the survey. This figure takes into account all answers, without a gender breakdown. The family balancing and legal restriction questions present interesting data. Only approximately a third of respondents believe family balancing is ethical, and approximately two-thirds of respondents believe legal restrictions are necessary. The researcher suggests that the third that do not believe restrictions are necessary may also be the third that support family balancing. With only a third of the population supporting family balancing, why is this procedure prevalent in Jordan? Corresponding to this, why are there no legal regulations, when two-thirds of the represented population believes there should be?

Screening for genetic diseases through PGD seems to be largely supported, with seventy percent of the population supporting, or having no opinion about, the matter. This reinforces the information obtained from the interviews, in that the only very controversial aspect of PGD is in gender selection for family balancing.

**Figure 2: Is it ethical, with a gender breakdown**



Gender breakdown presents several interesting observations. Most noticeable is the significantly lower proportion of females who support family planning than males (approximately fifteen percent, compared to thirty-five percent for men). Taking into consideration the patriarchal nature of Jordanian society, this could be because in family balancing, boys are chosen more frequently than girls, and mothers are less willing to give up their potential daughters. However, despite the many more men than women who believe family balancing to be ethical, it is still less than fifty percent of male respondents who support the practice.

Both legal restrictions and screening for genetic diseases have more than fifty percent support from both genders. This is important because it means that one gender's opinion does not drastically affect the overall population's opinion.

Across the data set, women almost always have a more definite opinion than men. Other than in the legal restrictions category, where 'no opinion' is about equal for both genders (roughly fourteen percent), women have a higher proportion responding 'yes' or 'no,' and not 'no opinion.' The researcher suggests that this may be due to the women's status as future mothers. Manipulating fertilization and characteristics of future children more physically affects the woman more than the man. Women must go through the procedures that allow PGD to occur. Another possibility for the differences in decidedness of opinions is that women may generally have more access to education about reproductive health and services.

Ultimately, as demonstrated by the survey, there seems to be some definite patterns between beliefs and gender. Additionally, the data relays a lot of important information that can be used to suggest a more thorough investigation of why legal regulation does not exist, since such a large proportion of people support it. This also applies to family balancing; it should be investigated as to why the procedure remains a legal and promoted practice, when such a small proportion of people seem to support it.

## Conclusion

### *Analysis of Results*

As previously stated, the hypothesis that medical professionals perceive Preimplantation Genetic Diagnosis (PGD) as ethical, within a specific scope of circumstances is shown to be accurate by the interviews conducted. The medical professionals interviewed all have different backgrounds, in terms of education and medical practice. Some were educated in Jordan, some abroad. Some have conducted their whole practice in Jordan; some have moved their work from abroad back to Jordan. These factors have altered their ethical perceptions, as ethics differ from region to region. Ultimately, the large number of opinions expressed demonstrates to what extent opinions can differ, even within a small population. This research only accessed five professional opinions. If a greater proportion of this population could be reached, an even broader understanding of these perceptions could be obtained.

The survey results yielded the anticipated data. As hypothesized, there appears to be a pattern between gender and ethical perceptions of different PGD procedures. In order to gain a true representation of young adults' opinions on this issue, a larger sample size would need to be obtained, but for the purpose of this research, an adequate number of surveyed opinions were achieved.

The survey data obtained is noteworthy because of the legality issues present in PGD, as well as the weak support of family planning. Especially as expressed by the female population surveyed, family planning should not be offered. The majority of the population reached believes legal regulations should exist. Neither of these conclusions corresponds to the current situation in Jordan, where there are no legal regulations of PGD, and family planning is certainly an option in reproductive services.

It should also be noted that there were some problems with the survey method of data collection. As previously mentioned, the population turned out to be fairly homogeneous in terms of demographic background. There was also some confusion as to what the questions were asking about, despite the brief explanation of terms at the beginning of the survey. In retrospect, there should have been a more in-depth, less scientific description of PGD, the different procedure scenarios, and debriefing of what the sought after perceptions entailed.

### *Connection to Theory*

The interviews conducted in this research reinforce Thomas Csordas' idea that morality is a cultural system. Expressed by the medical professionals, reasons for family balancing are completely based in culture, religion, or societal tradition. Interestingly, genetic screening was presented as less of a culture-based phenomenon, and more as a moral duty. Essentially, why would future parents not want to do what they can to guarantee the least amount of suffering as they can for their future child?

If applying Kant and Mill's theories to the perceptions gained in this research, it seems that family balancing justification does not lie in either utilitarianism or deontological ideals, while genetic screening could fall under Kant's theory of moral duty. Family balancing for the purpose of having a son is done for the perceived future benefit of the parents, and is a selfish, ignoring theological and philosophical ethics.

Genetic screening – that for both sex-linked diseases and non – has the potential to eliminate a large cause for suffering in future generations. It may be seen as a moral duty of scientists and parents alike to do all they can to assure this utilization of modern medical technology. Up until the point of causing more negative repercussions than positive results, doctors see genetic screening as a duty. Parents and doctors globally can be expected to view the procedure in the same light. The problem arises that not all people do see genetic screening as a duty. In order to understand and address this breakdown further, more in depth and comprehensive research would need to be conducted. Additionally, it is the opinion of the researcher that comprehending the societal effect (both physical and mental) of eliminating many genetic diseases would need to be analyzed for a broader understanding of moral duty in PGD.

Like the publications reviewed for this paper, these research results do not yield consensus in perceptions of ethics behind Preimplantation Genetic Diagnosis. Neither the interviews nor the surveys produced results that can be used in identifying reasons behind ethical perceptions. Noteworthy results include the lack of correlation between measured opinions regarding legal restrictions and family planning, and the current state of these in Jordan. Also, the collective opinion of medical professionals interviewed that there are limits to when PGD should and should not be used, is an important result. As with any research, this project has shown its limitations, which fuel the need for related future research.

## Study Limitations

Thorough research conducted on topics relating to ethics requires a comprehensive review of historical, political, and cultural context. Fieldwork should involve a fairly representative percentage of the relevant population, and include an adequate proportion of different groups within the society. In order for a more complete research study to occur, much more time and many more resources are needed than have been allowed for this project.

The topic of this study focuses solely on medical professionals involved in Preimplantation Genetic Diagnosis, and then surveys a slightly broader population in order to make the timeline feasible, as it only allowed three weeks for project completion. While medical professionals' opinions are key to understanding the ethical reasoning behind gender selection and genetic screening, a broader societal opinion would be necessary in order to draw conclusions about the population's outlook. Interviewing a wider selection of people would have been more difficult due to the sensitive nature of the material discussed, as well as an existing language barrier. As suggested by the refusal of some medical professionals to participate in interviews, if this study had included a broader population to interview, there would have been more hesitation and refusal. This would have been an additional hurdle in completing the research, and one that would need more time to overcome.

Availability of resources – financial and other – has also been a study limitation for this research. Should a more thorough look into the ethics of PGD be desired, there would need to be a funding body. This would not only allow for more time to be spent on the research, but it would also legitimize the research, as funded research oftentimes reinforces the necessity and intentionality of a research project. Human resources were another limiting factor. The researcher's position as a student, and as a non-expert on neither ethics nor the scientific procedure of PGD meant that the research process was stunted by a need to learn about the background of PGD and bioethics, while engaged in the research process.

## Further Recommendations

As shown throughout the survey portion of this research, there needs to be increased awareness regarding Preimplantation Genetic Diagnosis (PGD), and all of its aspects. Awareness does not only need to be raised if legal regulation should change, but also for the general knowledge of the population. If people do not know what reproductive aid options are available, a stratified demographic will be the only ones seeking the procedures.

If only a certain demographic aims to use reproductive services like PGD, then some social implications will develop. PGD may be more and more associated with the upper class, and it will become a privilege of those who know to access it. This may also occur due to the financial expense of PGD. Because of this, education about PGD should be widely available. Additionally, there should be restrictions on the cost of PGD services. If it is offered as a medical procedure, insurance companies should develop a plan to help cover some of the costs of the services.

Because of the apparent contradiction between Islamic belief and gender selection, an official *fatwa* should be passed regarding family balancing. In a society where the law is based on religious code, it is important for sensitive topics, such as PGD, to be addressed by the religious community.

As is the case upon the completion of most research, this project has demonstrated the need for future research on ethical perceptions behind Preimplantation Genetic Diagnosis. Not only ethics of the procedure in general, but also about the implications culture, religion, demographic background, and social tradition has on these opinions. Also, as the procedures become more widely available and as the technology expands, there needs to be research done on where the limitations of medical intervention in reproduction should be. Legal issues need to be addressed, in terms of how laws should be determined for gender selection and genetic screening. Research on how different populations view the same issue would be helpful for a more comprehensive understanding of the global position on PGD. Finally, research on how much education about PGD and other reproductive aid technology is available should be done in order to gauge how society should further educate its population on the medical issues that may have extensive social implications in the future.

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## Appendices

**Survey:** 20-30 year olds' Views on Preimplantation Genetic Diagnosis

*Key terms defined:*

**PGD**: Preimplantation Genetic Diagnosis – allows for testing of embryos prior to in vitro fertilization

**IVF**: In vitro fertilization of embryos

**1.** Age: _______

**2.** Gender: M F

**3.** Educational Attainment (highest obtained or that which you are currently enrolled):

a. Grade School b. High School
c. Associate's Degree d. Bachelor's Degree
e. Master's Degree f. Doctorate Degree

**4.** Nationality: ___________________

**5.** Religious Affiliation: ________________

**6.** Marital Status:

a. Married, without children b. Married, with children
c. Engaged d. Single
e. Other ___________________

**7.** Do you perceive gender selection for family balancing (choosing a boy or girl because you already have the other) as ethical?

Yes No No opinion

**8.** Do you perceive gender selection for the purpose of screening out gender-related diseases as ethical?

Yes No No opinion

**9.** Do you perceive PGD (before fertilization through IVF) for the purpose of screening out genetic diseases as ethical?

Yes No No opinion

**10.** Do you believe there should be legal regulations as to what may be done through genetic testing of embryos?

Yes No No opinion

Thank you for your participation.

Any questions may be directed towards:

Sarah C Miller
SIT Jordan: Health and Community Development
millersc@kenyon.edu

## Interview Guide

### *Introduction*

First, allow me to thank you for your time and contribution to this study. The research topic is the measuring the perceived ethical considerations Preimplantation Genetic Diagnosis (PGD), as seen by medical professionals who perform the procedure, as well as young adults' who may affect the future development of PGD. Today, I would like to talk to you about your views regarding PGD, especially as it is used for gender selection and genetic screening. We will begin with basic objective questions, and then move towards the more subjective material. Your responses will be kept anonymous and confidential. Upon the conclusion of this study, a final paper will be available if requested. Lastly, if you consent to it, this interview will be recorded in order to provide a more exact reporting of the interview during the research analysis. After the conclusion of the study, the recordings will be deleted.

### *Interview questions*

*1.* (If consented) Please confirm that you have consented to this interview being tape-recorded.

*2.* How long have you been involved in Preimplantation Genetic Diagnosis?

*3.* Do you perceive PGD as ethical?

-Should potential parents be able to select the gender of their future child? Why?

-Do you see gender selection as a cultural phenomenon?

-Does your religious belief factor into your beliefs?

-When used for genetic screening, are there limits to what should and should not be screened out?

*6.* Are there limits in how PGD should be used?

*7.* How will PGD develop in the future?

*8.* Do you have any concluding comments?

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## CONSENT FORM: Interviewee

1. **Brief description of the purpose of this study**
   The purpose of this study is to further understand the ethical considerations and limits of Preimplantation Genetic Diagnosis (PGD), as perceived by medical professionals and patients who may be engaging in such procedures. The voluntary participation of doctors who offer PGD to be interviewed is necessary in order to access the sought perceptions. By signing this form, the interviewee indicates willingness for the data to be used in this study and a future dissertation of the researcher's.
2. **Rights Notice**

   In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.
   - **a.** ***Privacy*** - all information you present may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.

   - **b.** ***Anonymity*** - all names in this study will be kept anonymous unless the participant chooses otherwise.

   - **c.** ***Confidentiality*** - all names will remain completely confidential and fully protected by the researcher. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The researcher will also sign a copy of this contract and give it to the participant.

| | |
|---|---|
| Interviewee's name printed | Interviewee's signature and date |
| Researcher's name printed | Researcher's signature and date |

Note: Consent of those surveyed was indicated by their completion of the survey. Because of the nature of anonymous, public surveys, there was not need for written signed consent prior to surveys. This was explained to participants upon distribution.

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Student Signature: Sarah C Miller Date: 05 December 2013