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# Preimplantation Genetic Diagnosis: Physician Assistants' Perspectives, Understandings, and Ethical Considerations

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# PREIMPLANTATION GENETIC DIAGNOSIS: PHYSICIAN ASSISTANTS' PERSPECTIVES, UNDERSTANDINGS, AND ETHICAL CONSIDERATIONS

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## Abstract

While factors contributing to rates of approval and disapproval of preimplantation genetic diagnosis (PGD) have been studied at length, the perspective of Physician Assistants' (PA) approval and disapproval of PGD has not been studied, nor the common reasons why PAs approve or disapprove of PGD. The first goal of this study was to identify approval and disapproval rates of PGD amongst PAs. The next goal was to identify common reasons PAs approve or disapprove of PGD utilization. Members of the California Academy of Physician Assistants [CAPA (CA)] and Kansas Academy of Physician Assistants [KAPA (KS)] completed an adapted, electronic survey that assessed individual approval and disapproval rates of PGD, and the common reasons why. Regarding the use of PGD, 43% of the participants agreed or strongly agreed with the use of PGD for Mendelian conditions. The most common reasons participants agreed were: PGD improves the chances of a healthy child and couples' autonomy. Most commonly cited reasons of disapproval of the Mendelian use of PGD were: PGD interferes with nature and places providers in the role of "Playing God", and PGD promotes discrimination. Opinions regarding Non-Mendelian use of PGD were more stratified, with 93% disagreeing or strongly disagreeing with PGD utilization for Non-Mendelian screening. The common reasons of disapproval of PGD were: PGD promotes discrimination against people with certain characteristics, PGD interferes with nature and places providers in the role of "playing God", widespread use of PGD may lead to unforeseen consequences, and PGD leads to unnecessary destruction of embryos.

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# Chapter 1: Introduction

## Introduction

The following chapter will highlight the history of reproductive genetics, advancements in reproductive technology, and preimplantation genetic diagnosis (PGD). This chapter outlines the background, problem statement, purpose, significance, research questions, and definitions of terms of this study.

## Background

The understanding of genetics began in 1865 with Gregor Mendel (National Human Genome Research Institute, 2014). Historically considered the father of genetics, Mendel discovered that traits are transmitted in discrete units called genes, along with inheritance patterns. The discovery of inheritance patterns supported Charles Darwin's notion of natural selection in 1859, which explained that the genetics best fit for survival will be inherited in subsequent generations (National Human Genome Research Institute, 2014).

Discovery and advancements in the understanding of genetics have allowed for reproductive genetic technology to make extensive progress. The first trial experiments of in-vitro fertilization (IVF) procedures were conducted in the early 1900's (Franasiak & Scott, n.d.). Since the first successful IVF birth in 1978, the development of IVF enabled the research and understanding of embryo development (Franasiak & Scott, n.d.). IVF played a central role in advancing infertility success and helping couples achieve successful pregnancies (Franasiak & Scott, n.d.). On the basis of IVF, technologies have advanced to implement embryo screening and selection (Franasiak & Scott, n.d.). The procedure of screening, distinguishing, and selecting embryos that are reproductively competent and free from genetic diseases or chromosomal defects is known as preimplantation genetic diagnosis (PGD) (Franasiak & Scott,

n.d.). PGD can identify the presence of chromosomal translocations and single-gene disorders (Fertility Center of New England, n.d.). The goal of PGD is to distinguish those embryos that are capable of producing a healthy child from those that cannot in order to improve rates of successful pregnancies, while minimizing risk of genetic or chromosomal complications, and miscarriages and pregnancy terminations (abortions) (Franasiak & Scott, n.d.). In 1990, the first successful child following PGD was born (Franasiak & Scott, n.d.). Thereafter, PGD technology has advanced with expanded indications and worldwide utilizations (Franasiak & Scott, n.d.).

With advancements in genetics, specifically embryonic research, ethical controversies emerge. PGD is no exception. A wide spectrum of understandings, perspectives, and ethical considerations manifest, with respect to PGD utilization, both in the general population and in the medical community. Preimplantation genetic screening (PGS) uses one aspect of the PGD process, allowing for identification of aneuploid embryos. PGD includes this aneuploidy screening, and adds additional testing for other genetic markers (Weissman et al., 2017; Fertility Centers of New England, 2013). A study conducted by Weissman et al. (2017) analyzed the applications for PGS and factors influencing the utilization and restriction of PGS worldwide. Results of the study showed that utilization of PGS were largely for women older than the age of 35 and women with a history of implantation failure or recurrent pregnancy loss (Weissman et al., 2017). Factors inhibiting worldwide use of PGS included legislation, low demand, and cost/staffing considerations (Weissman et al., 2017). Of IVF clinic respondents, a majority believed PGS could prevent transfer of aneuploid embryos and increase live birth rates while conversely reducing miscarriage rates (Weissman et al., 2017).

Diving deeper than the utilizations and restrictions of PGS and PGD, a Princeton Survey Research Associates conducted a United States survey in 2002 to address public awareness and

attitudes on genetic testing. Most commonly supported reasons for using PGD included: avoiding serious genetic disease such as autosomal dominant conditions, ensuring a child was a blood match of the ABO and Rh factor to that of the living sibling for potential transfusions and transplantations, and avoiding genetic diseases such as cancer, cystic fibrosis, Huntington Disease, or sickle cell disease (Princeton Survey Research Associates, 2002). The majority of respondents approved IVF and prenatal testing for genetic diseases or chromosomal defects (Princeton Survey Research Associates, 2002).

Other perspectives exist within the general public regarding the use of PGD. A meta-analysis of public perspectives towards using PGD to detect hereditary cancers, revealed a lack of knowledge and understanding of PGD (Quinn, Pal, Murphy, Vadaparampil, & Kumar, 2011). About one third of respondents had no knowledge about PGD (Quinn et al., 2011). A majority believed PGD should be offered to those affected by hereditary cancers, and half would consider personally using PGD if a hereditary cancer was a concern (Quinn et al., 2011).

Based on a 2013 survey by Harris Interactive Service Bureau, public perspectives on PGD varied (Winkelman, Missmer, Myers, & Ginsburg, 2015). A majority favored PGD, especially for the purpose of reducing fatalities early in life and eliminating lifelong disabilities (Winkelman et al., 2015). The most common reasons for favoring PGD were that couples should have reproductive autonomy and improve the chances of a healthy child. Those opposing PGD, commonly did so because PGD interferes with nature, and widespread PGD use may lead to unforeseen consequences (Winkelman et al., 2015).

In addition to evaluating public perspectives, physician viewpoints on PGD have also been studied. Specific specialties that have been screened include internists, pediatricians, genetic professionals, neurologists, psychiatrists, obstetricians, and gynecologists. A 2012

United States survey by Klitzman et al. (2013), revealed internists were most likely to recommend PGD for cystic fibrosis patients (33.7%) and breast cancer patients (23.5%). Based on a Chicago qualitative study of pediatricians and parents by Campbell & Ross (2004), pediatricians were more hesitant than parents to screen for genetic links to criminal behavior. Another study revealed only a small percentage (2.4%) of psychiatrists and neurologists discussed PGD with their patients (Abbate et al., 2014). Psychiatrists and neurologists were most likely to refer to PGD for Huntington's disease, Tay-Sachs, and cystic fibrosis (Abbate et al., 2014). In a 2010 United States survey, only 17% of obstetricians and gynecologists felt like they were knowledgeable about PGD (Abbate et al., 2014). Physicians' support for PGD was highest with the aim to avoid serious and life-threatening genetic diseases, and lowest when considering less serious diseases or sex selection. A general trend for the need for increased provider education was also observed (Abbate et al., 2014).

**Problem Statement**

Several research studies have been conducted analyzing both the general public's and physicians' perspectives, understandings, and ethical considerations about PGD. Currently, no clear consensus exists in the public or medical community for when, how, or why PGD should or can be used. Amidst the literature, research on PAs' approval and disapproval of PGD use for Mendelian vs. Non-Mendelian disorders and the common reasons of approval and disapproval of the utilization of PGD is absent. This lack of research raises the importance of obtaining data of PAs' understanding and opinions towards PGD. Our study aimed to fill this void.

**Purpose of the Study**

The purpose of this study was to survey members of California Academy of Physician Assistants [CAPA (CA)] and members of Kansas Academy of Physician Assistants [KAPA

(KS)] regarding the percentage of PAs that approve and disapprove of PGD use for Mendelian vs. Non-Mendelian disorders, and the common reasons that PAs approve and disapprove the utilization of PGD. Furthermore, this study analyzed the understandings that PAs have of the PGD definition and process.

**Significance of the Study**

As indicated from data conducted by the NCCPA (2016), the PA profession has grown 35.9% from 2010-2015. According to the Bureau of Labor Statistics, the projected growth of PAs is 37% from 2016 to 2026 ("2015 Statistical profile," 2016 & Bureau of Labor Statistics, 2017). Due to this large expansion of practicing PAs, in combination with the continuing advancements in reproductive technology and PGD, it will be increasingly important for PAs to understand PGD and be able to discuss PGD effectively with their patients (Hudson, 2006).

Research conducted by Hudson (2006) indicated that as the general public gains knowledge about advancing reproductive technology, their perspectives, understandings, and ethical considerations on PGD utilization fluctuated. Many misconceptions exist, regarding the development and purpose of PGD. With increased general public interest in PGD, the role of the PA is crucial in educating and guiding patients (Hudson, 2006). Regardless of the field in which a PA may work, patients with inheritable conditions will present to them for care. These patients may want to reproduce but have fertility difficulties or risk of passing on genetic conditions (Hudson, 2006). Because PAs provide education and guidance to patients on a variety of topics, including reproductive medicine and genetic diseases, PA knowledge about PGD is essential (Abbate et al., 2014; Hudson, 2006).

The understanding of PGD is critical for PAs, as well as all medical providers, as potential controversies arise. This study provided information about the current percentage of

PAs that approve and disapprove of PGD use for Mendelian vs. Non-Mendelian disorders and the common reasons that PAs approve and disapprove of the utilization of PGD, which could provide insight for the future when considering how PAs can be educated to effectively address the topic of PGD with patients.

**Research Questions**

This study attempted to answer the following research questions:

1. What is the percentage of PAs that approve of PGD use for Mendelian vs. Non-Mendelian disorders?
2. What is the percentage of PAs that disapprove of PGD use for Mendelian vs. Non-Mendelian disorders?
3. What are the most common reasons PAs approve the use of PGD?
4. What are the most common reasons PAs disapprove the use of PGD?

**Definition of Terms**

The following definition of terms are essential to understanding this study.

Chromosomal abnormality: result from mutations which change the number of chromosomes (numerical abnormalities) or change the structure of the chromosome (structural abnormalities). Chromosomal abnormalities may alter the ability of the cell to survive and function ("Chromosome abnormalities," 2017).

Embryo: the early developmental stage of an animal following conception until the end of the seventh week since conception ("Embryo," 2016).

Gene Probe: a unique probe that is custom designed for each couple to analyze the DNA from the cells removed from the embryo, for the specific gene mutation at specific loci in short tandem repeats. ("Preimplantation Genetic Diagnosis," n.d.; "Karyomapping," 2014).

Genetic disorder: a disease caused by a change in the DNA sequence from the normal sequence. Genetic disorders from a mutation in one gene, mutations in multiple genes, combination of gene mutations and environmental factors, or by damage to chromosomes. ("Frequently asked questions," 2015).

In vitro fertilization (IVF): fertilization of a human egg in laboratory dish or test tube. Specifically, fertilization occurs by mixing sperm with eggs, surgically removed from an ovary. The sperm fertilizes the egg to create an embryo, which is transferred into a prepared uterus ("In vitro fertilization," 2017).

Karyomapping: involves a technique of genome-wide linkage analysis, in which numerous single nucleotide polymorphisms (SNP) within the genome are genotyped in the two parents and their embryos to determine whether an embryo has a genetic defect (Gimenez et al., 2015).

Mendelian disorder: a genetic disease showing a specific pattern of inheritance by means of dominant and recessive alleles, resulting from a single mutation in the structure of DNA at one genetic locus, which creates a single basic defect that has some pathological consequence(s) ("Mendelian disorder," n.d.).

Non-Mendelian condition: any complex genetic disease-e.g., hypertension, diabetes mellitus, arteriosclerotic heart disease, which does not follow a simple mendelian pattern of inheritance and involves more than one gene ("Nonmendelian disorder," 2002).

Physician assistant (PA): is a nationally certified and state-licensed medical professional ("What is a PA?," n.d.).

Polymerase chain reaction (PCR): an in vitro technique for rapidly synthesizing large quantities of a specific DNA segment that involves separating the DNA into its two complementary

strands. Utilizing DNA polymerase to synthesize two stranded DNA from each single strand, and repeating the process numerous times ("Polymerase chain reaction," n.d.).

Preimplantation genetic diagnosis (PGD): is defined as the testing of preimplantation stage oocyte polar bodies and zygotes/embryos for chromosomal defects and genetic defects with the use of karyomapping or a gene probe (Geraedts & De Wert, 2009).

Preimplantation genetic screening (PGS): screening to identify de-novo aneuploidy, including subchromosomal deletions and additions, in embryos of couples known (or presumed) to be euploid (Schattman & Kangpu, 2017).

**Conclusion**

As stated in the problem statement, purpose, and significance of this study, the importance of improving understandings of PGD and PA knowledge and views of PGD is apparent. The literature review in Chapter Two will define PGD, describe the history of PGD, indications and utilizations for the procedure, and the process of PGD technique. Chapter Two introduces the ethical controversies surrounding PGD regulations and utilizations. A majority of the next chapter will discuss past research, which analyzes both the general public's and physicians' understandings and perspectives towards PGD.

# Chapter 2: Literature Review

## Introduction

Preimplantation genetic diagnosis (PGD) is a procedure which analyzes the genetic makeup of single cells biopsied from oocyte polar bodies or embryos, formed through in vitro fertilization (IVF) (Traeger, 2017). The embryos are screened to determine any chromosomal abnormalities. Normal embryos are selected for transfer to the prepared uterus. The goal is to eliminate chromosomal/genetic defects and achieve an unaffected pregnancy (Khalaf, 2007). PGD was developed to aid couples with an unsuccessful reproductive history and couples whose potential offspring may be at a genetic risk for Mendelian disorders, mitochondrial disorders, or structural chromosome abnormalities (Geraedts & De Wert, 2009).

PGD is a multi-step procedure overseen by a collaboration of specialized gynecologists, embryologists, and geneticists (Traeger, 2017). The process of PGD involves close collaboration between reproductive endocrinologists who are experts in assisted reproduction, embryologists who specialize in embryo biopsy and germ cell details, and geneticists who specialize in the genetic analysis at the single-cell level (Traeger, 2017). PGD is considered a form of prenatal diagnosis (Traeger, 2017). The utilization of PGD advances beyond previous prenatal diagnosis techniques. The most common forms of prenatal testing are amniocentesis or chorionic villi sampling, which involve testing the chromosomal makeup of a developing fetus for abnormal chromosomal conditions. These methods accurately identify chromosomal disorders during pregnancy (Traeger, 2017). If defects are discovered, difficult decisions for parents may be provoked. According to Traeger (2017) and Bick & Lau (2006), the advantage of PGD is that it supported the selection of a normal embryo prior to implantation which substantially reduced the considerations of terminating an affected pregnancy.

Countless opinions exist both supporting and opposing PGD. This literature review analyzes understandings and perspectives of the public and medical communities. This chapter will introduce the history, laboratory process, indications, and uses of PGD. After addressing the ethical considerations and regulations regarding PGD, the literature review will discuss past research, present research, and worldwide perspectives on the use of PGD with regard to the general public and physicians.

**History of Preimplantation Genetic Diagnosis**

In the late 19th century, Sir Walter Heape, a professor at the University of Cambridge in the United Kingdom, introduced the concept of assisted reproductive technologies by successfully transplanting rabbit embryos (Kamel, 2013). In 1934, this concept of experimenting with assisted reproduction was revisited. After mixing rabbit sperm and egg in vitro, Gregory Pincus, PhD, implanted the developing embryo into a rabbit (Kamel, 2013). Between 1944 and 1948, Dr. John Rock, a clinical professor at Harvard Medical School, and his assistant Miriam Menkin, completed a series of human embryo IVF experiments (Countway Repository, 2009). Although not successful for human life, this sparked the progression of human IVF development (Countway Repository, 2009).

In 1966, the first karyotype following amniotic fluid sampling was performed (Vermeesch, Voet, & Devriendt, 2016). In 1967, the first prenatal karyotype of a chromosomal abnormality was identified (Vermeesch, Voet, & Devriendt, 2016). In 1968, the possibility of PGD in animals was prompted (Vermeesch, Voet, & Devriendt, 2016). In 1973, the first human IVF pregnancy was reported in Australia, but was unsuccessful after one week (Kamel, 2013). Subsequently, in the UK, Patrick Christopher Steptoe, MD, and physiologist Robert Geoffrey Edwards created the first “test-tube baby” (Kamel, 2013). In July 1978, Lesley Brown gave birth

to a healthy baby girl, Louise Brown, which was a breakthrough in assisted human reproductive technology (Kamel, 2013). The success of IVF enabled the success of PGD on human embryos, among other reproductive technologies (Kamel, 2013).

In 1980, Alan Handyside, PhD, of the United Kingdom introduced PGD to identify chromosomal defects in embryos by cell biopsy (Kamel, 2013). The process of cell biopsy was developed as an alternative to post-implantation prenatal testing. In 1989, the first report was published on biopsying a pre-implanted embryo and detecting the sex using DNA amplification (Kamel, 2013). The first applications for PGD were used to test monogenic disorders and sex-linked disorders, which was made possible by Elana Kontogianni's work showing polymerase chain reaction (PCR) for the Y chromosome was possible from a blastomere (Franasiak & Scott, n.d.). Researchers were able to focus on X-chromosome linked diseases by amplifying and detecting the Y-chromosome specific repeat sequences to select for embryos that were female; thus, not affected by the X-linked disease. Original approaches to such discoveries led to newer technologies that detected gene mutations on autosomes and sex chromosomes, allowing for the selection of mutation free embryos for transfer in pregnancy (Franasiak & Scott, n.d.). In 1990, Handyside and colleagues assisted with the first successful childbirth following PGD for sex selection of embryos in attempt to avoid an X-linked genetic disorder (Kamel, 2013). As the first polar body biopsy for PGD, this involved selecting for the female embryos to eliminate the risk of male embryos being affected by the X-linked defect (Kamel, 2013). In 1992, the first live births occurred after identifying and selecting against the autosomal recessive disorder, cystic fibrosis (Kamel, 2013). In 1999, the first pregnancy was successful when PGD was used to select an embryo free from sickle cell anemia (Kamel, 2013). In 2001, PGD was used to select offspring that would have the potential to be a donor to siblings in a family with severe blood

disorders (Vermeesch, Voet, & Devriendt, 2016). Then in 2013, genome-wide haplotyping, or karyomapping, was commercialized by a company called Illumina, allowing a new method for selecting against embryos carrying Mendelian inherited disorders (Griffin & Gould, 2017).

Traditionally, the detection of single gene disorders in cells biopsied from preimplantation embryos has been done through a sensitive multiplex, PCR methodology in order to amplify specific DNA fragments to detectable concentrations (Gimenez et al., 2015). PCR amplification of the DNA allows for detection of the gene mutation site and/or linked polymorphisms. Problems within the amplification process exist such as allele drop out, which is failure to amplify one of the two parental alleles in the biopsied cell, and DNA contamination. Current standard practice guidelines recommend using both amplification and analysis of several closely linked polymorphisms, along with direct mutation detection (Gimenez et al., 2015). The process of optimizing a multiplex-PCR capable of amplifying all of the necessary loci from a single cell requires a significant amount of laboratory work developing a specific test for each patient, which can take months and higher costs (Gimenez et al, 2015). In the past, an older technology was used requiring development of a physical DNA probe which was used to test the embryos and now the term "probe," is a relatively outdated term (ORMgenomics, n.d.).

Invented in 2008 and commercialized in 2013, karyomapping was developed as the newest alternative to conventional PCR methods for PGD (Gimenez et. al, 2015; Griffin & Gould, 2017). The introduction of karyomapping not only greatly reduced the time required for embryonic testing prior to transfer, but also improved the accuracy of PGD (Gimenez et. al, 2015; ORMgenomics, n.d.). For all 23 pairs of chromosomes, karyomapping uses a universal set of markers across the whole genome (ORMgenomics, n.d.). These markers allow for the disease-causing gene to be located and tracked from parents to embryo (ORMgenomics, n.d.).

Rather than designing family-specific, and disease-specific tests for each couple, karyomapping allows for a single test to be applicable to all families for a majority of conditions (ORMgenomics, n.d.). This shift is due to the use of universal markers, which are spread across the genome (ORMgenomics, n.d.).

The process in karyomapping involves genome-wide linkage analysis, in which hundreds of thousands single nucleotide polymorphisms (SNP) within the genome are genotyped in the two parents and their embryos (Gimenez et al., 2015). Inheritance of chromosomal segments with the genes they contain can be followed down generations due to each chromosomal region having a unique SNP fingerprint. The SNP fingerprint of the parents can be compared to other family members with known genetic status, for example, another relative that is known carrier of the same mutation as of the parents. After analysis of the family genomes, a unique DNA fingerprint can be identified for that family using the combination of SNP alleles associated with a chromosome carrying a gene mutation (Gimenez et al., 2015). Embryos can then be tested against the DNA fingerprint to determine if they carry the normal or mutated gene, and the embryo carrying the SNP pattern mutation can be avoided for pregnancy (Gimenez et al., 2015; ORMgenomics, n.d.).

Karyomapping is a routine procedure for PGD which serves to be a powerful and versatile new approach for diagnosing single gene disorders in embryos. According to Gimenez et al. (2015), the karyomapping process allows for the possibility to expand past linkage analysis and provide direct detection of mutations, previously unseen by conventional PGD methods. Although karyomapping is not widely used yet for aneuploidy screening, researchers confirm karyomapping has the potential to combine strategies and provide aneuploidy screen and identification along with monogenic defects (Gimenez et al., 2015; Griffin & Gould, 2017). Due

to limited reliability detecting post-zygotic trisomy, karyomapping has not been fully implemented clinically for chromosomal aneuploidy screening (Griffin & Gould, 2017). As of 2017, karyomapping is currently used for the detection of monogenic disorders at approximately 1000 clinics worldwide (Griffin & Gould, 2017).

**Cell Acquisition and Extraction**

The following paragraphs will discuss the complex process of PGD, explaining how embryos are screened and selected during the initial stages of growth prior to implantation. The process of IVF and PGD begins when oocytes are collected from the female and sperm are collected from the male and both are then taken to the laboratory (Alberts et al., 1983). The oocyte is surrounded by an extracellular matrix, the zona pellucida. The acrosome of the sperm releases enzymes that lyse a portion of the zona pellucida, thus permitting the penetration of the egg by a single sperm resulting in the fusion of the sperm and the egg (Alberts et al., 1983). After fusion of the membranes, the haploid sperm nucleus combines with the haploid egg nucleus, producing a diploid nucleus of a fertilized egg, the zygote (Gilbert, 2000).

For approximately three days, the zygote is maintained on a laboratory dish until it reaches the eight-cell stage. At this point, biopsy is safe and can be performed because the removal of cell(s) will not have detrimental effects on the growth of the embryo (Antonios, 2011). Polar-body biopsy, cleavage-stage biopsy, or blastocyst biopsy are the three most commonly used techniques to remove a cell or cells from the embryo for analysis (Thornhill & Snow, 2002). These processes share a similar step of opening the zona pellucida via either sharp microneedle, acidified Tyrode's solution with a pH 2.2, or by thermal ablation with a non-contact laser. The cell(s) are removed by a micropipette or a hydraulic base suction system (Thornhill & Snow, 2002).

Polar-body biopsy, cleavage stage biopsy, and blastocyst trophectoderm biopsy are the three most commonly utilized extraction methods to obtain a cell or multiple cells for their genetic information for further analysis (Kuliev & Rechitsky, 2011). Kokkali et al. (2007) compared cleavage stage biopsy and blastocyst biopsy methods by comparing 20 embryos of 20 couples, all affected by β-thalassaemia. The embryos were placed into two groups, one undergoing cleavage stage biopsy and the other blastocyst biopsy. In the conclusion of this study, cleavage stage biopsy and polar body biopsy, which remove one or two cells from the embryo, resulted in a lack of genetic material available for amplification, while the blastocyst biopsy resulted in larger amounts of genetic material for analysis.

The lack of genetic material for amplification indicates that the embryo is still viable for implantation but utilizing PGD would be difficult to complete due to the lack of genetic material for analysis (Kuliev & Rechitsky, 2011). Only 75.2% of cases utilizing cleavage stage biopsy and polar body biopsy had enough genetic material due to only removing one or two cells for genetic analysis (Kuliev & Rechitsky, 2011). Having only one or two cells' genetic material often results in inadequate amplification during each cycle of PGD (Kuliev & Rechitsky, 2011). Utilizing the blastocyst biopsy, where the embryo is cultured for a longer period prior to removal of four to five cells, resulted in 94.3% of cases having enough genetic material for accurate amplification (Kuliev & Rechitsky, 2011). The amplification process has more genetic material for testing, decreasing the likelihood of amplification failure. As a result, the PGD process is able to obtain enough genetic material for amplification and accurate genetic analysis utilizing blastocyst biopsies (Kokkali et al., 2007).

**Indications and Utilizations for Preimplantation Genetic Diagnosis**

A 2017 national survey by the Center for Disease Control revealed that 4% of 208,604 cycles of IVF in the US involved PGS and/or PGD (Weissman et al., 2017). The Society for Assisted Reproductive Technology reported that 165 out of 458 (36%) participating clinics used PGD, PGS, or both (Weissman et al., 2017). According to Weissman et al. (2017), this data is likely an underestimation. Due to the increasing popularity of PGD and PGS and due to no updated data available, the researchers estimate over 20% or more of IVF cycles in the US currently involve PGS or PGD (Weissman et al., 2017).

Initially, PGD was used for the selection of embryos for couples who were carriers of sex-linked diseases, and for determination of gender (IVF-Worldwide, n.d.). PGD quickly progressed and today is indicated for identifying single gene mutations, structural chromosomal abnormalities, abnormal number of chromosomes, tissue/human leukocyte antigen type, and gender (IVF-Worldwide, n.d.). PGD can be considered for women of advanced maternal age >35, couples with recurrent miscarriages, several failed IVF cycles, or prior pregnancy with a chromosome abnormality, or where at least one partner has aneuploidy mosaicism or is a carrier of an X-linked disease or structural chromosome rearrangement (IVF-Worldwide, n.d.). PGD is intended for men who test positive to aneuploidy sperm screening or with infertility requiring intracytoplasmic sperm injection (IVF-Worldwide, n.d.). PGD is most commonly used to identify autosomal dominant diseases such as familial hypercholesterolemia, polycystic kidney disease, or Huntington's disease. PGD is used to detect autosomal recessive diseases such as sickle cell anemia, cystic fibrosis, or Tay-Sachs disease. PGD can identify X-linked diseases of Duchenne muscular dystrophy or hemophilia, or chromosomal abnormalities such as Down Syndrome (IVF-Worldwide, n.d.). PGD can also be used to diagnose late-onset diseases and

predisposition syndromes such as cancer risk factors or Huntington's disease. For example, PGD can be used to find BRCA1 and BRCA2, hereditary breast and ovarian cancer genes, by allowing parents to choose embryos free from these genes decreasing risk for offspring to later develop the cancers (IVF-Worldwide, n.d.). The list of diseases, conditions, and syndromes that PGD can detect is extensive and is continuing to expand with advances in reproductive and genetic technologies.

As the utilization of PGD increased throughout the 2000's, Johns Hopkins Public Policy Center conducted a survey in 2008 on the prevalence and patterns of PGD usage in the United States (Stern, 2014). The study analyzed the number of advanced reproductive clinics in the United States utilizing PGD for aneuploidy testing, single gene disorders, structural chromosome rearrangements, X-linked disease, non-medical sex selection, avoidance of adult onset disorders, human antigen leukocyte typing, and selection for disability (Stern, 2014). The survey was sent to 415 clinics with responses from 186 clinics, of which, 137 clinics offered PGD services. Of these clinics, 82% performed IVF with PGD. The clinics provided 28% of testing services for adult onset disorders such as Huntington's Disease, hereditary breast and ovarian cancer, and Alzheimer's Disease. Of the clinics surveyed, 23% provided IVF/PGD for human leukocyte antigen typing; those intending to have another child who is an immunological match for a sibling that is ill. The survey data indicated 6% of the clinics provided testing services with the intention of having a child who is a match for an older sibling, where the new child is not at risk for having the disorder (Stern, 2014). Additionally, the study found that 42% of the clinics provided services of non-medical sex selection (Stern, 2014). Lastly, 3% responded that PGD was utilized for the purpose of selection of embryos for a specific disease or disability, such as deafness or dwarfism (Stern, 2014).

**Ethical Considerations**

Each indication for PGD evokes associated ethical considerations. Initially, the primary use of PGD testing was for Mendelian disorders, which includes genetic diseases such as cystic fibrosis, Huntington Disease, or sickle cell disease (Imudia & Plosker, 2016). This indication tends to produce fewer controversial arguments, as it involves testing the embryos for diseases that can be detrimental to the offspring (Imudia & Plosker, 2016). Use of PGD for Non-Mendelian conditions creates more controversial considerations (Imudia & Plosker, 2016). Non-Mendelian conditions include: human leukocyte antigen typing, non-medical sex selection, non-medical trait selection, and selection of embryos for disability and disease (Stern, 2014); (Boyle & Savulescu, 2001); ("Nonmendelian disorder," 2002).

Human leukocyte antigen typing is a potential use of PGD that is categorized under Non-Mendelian conditions. The testing and development of the "savior sibling" involves using PGD to screen and select an embryo to be a genetic match to a living sibling (Stern, 2014, pp. 280-309). The embryo is implanted with the intention of utilizing a stem cell or organ donation to "save" the sibling (Stern, 2014). The ethical considerations surrounding human leukocyte antigen typing include: the "savior sibling" having the capacity to consent or object to serve as the donor, the best interest of the "savior sibling," and if the "savior sibling" will be loved (Stern, 2014).

According to Boyle & Savulescu (2001), couples requesting human leukocyte antigen typing love and appreciate the child, the child feels value in saving the life of the sibling, and there are minimal psychological effects from being the "savior sibling." In the United Kingdom, the Human Fertilisation and Embryology Authority, HFEA, reports that PGD is approved for the use of "savior siblings," if the child born after PGD is at risk of also having the condition the

existing child is experiencing (Robertson, 2003, pp. 465-471). For example, human leukocyte antigen typing is approved for Fanconi's anemia, but not for the use of childhood leukemia or lymphoma without genetic mutation (Robertson, 2003). A study conducted by Johns Hopkins Institutional Review Board in April 2004, found that 66% of 6,000 general public participants approved of utilizing PGD for human antigen leukocyte typing (Hudson, 2006). Additionally, supporters of PGD for human antigen leukocyte typing stated that use of PGD would fulfill two functions: the selection of disease-free embryos and the selection of a compatible stem cell donor (Boyle & Savulescu, 2001).

Another Non-Mendelian use of PGD is non-medical sex selection, which poses the question of gender bias (Boyle & Savulescu, 2001). The argument opposing the use of PGD for non-medical sex selection is that selecting for preferred gender could lead to imbalance of the sexes in the population (Robertson, 2003). For example, many countries have the preferred sex of the first child to be a male (Robertson, 2003). If sex-selection through PGD was utilized frequently in these countries, the sex ratio would become unequal in certain populations (Robertson, 2003). Perspectives on the use of PGD for gender selection is mixed. An article by Robertson (2003), stated that utilizing PGD for the selection of a couple's first child is oftentimes labeled as sexist, due to the highly preferred gender the couple is requesting (Robertson, 2003). However, Robertson (2003) stated that if a couple already has one child conceived without the use of PGD for gender selection, subsequent children obtained through PGD would not be labeled as a sexist selection. For example, if a couple has two male children, and utilizes PGD to have a female child, this would not be labeled as sexist. However, if a couple were to utilize PGD to have their first child, this would be labeled as sexist because of the high rate of male preference, primarily seen in India and China (Robertson, 2003). The

American Society of Reproductive Medicine, ASRM, stated that sex selection through PGD should be "discouraged" as there is not enough evidence about the topic (Robertson, 2003, pp. 465-471).

An additional ethical consideration arises with using PGD for non-medical trait selection. The use of PGD for non-medical trait selection is an attempt to choose traits of parental preference and to help the child "have every possible advantage" (Hudson, 2006). In a study conducted by Winkelman, Missmer, Myers, and Ginsburg, a survey of 1006 respondents of the general population responded with 14.6% approval rate of PGD for physical selection and 18.9% approval rate of PGD for personality traits (2015). However, utilizing PGD for non-medical trait selection, poses the ethical consideration of "playing God" (Boyle & Savelescu, 2001, pp. 1240-1243). Johns Hopkins Institutional Review Board in April 2004, found that 72% of 6,000 participants disapprove of utilizing PGD testing for non-medically related traits (Hudson, 2006). The Bioethics Council in the United States, reported that "human reproduction is a 'gift' and that any form of selection or manipulation turns the child into a 'manufacture' and thus impairs human flourishing" (Robertson, 2003, pp. 465-471). Once selection of traits becomes frequently requested, the concept of "designer babies," which involves the selection of preferred genes the embryo will utilize for development, will result in non-medical trait selection to become even more controversial. Additionally, non-medical trait selection and the future possibility of "designer babies" poses the possibility of reduced genetic diversity (Boyle & Savulescu, 2001).

The selection of embryos for disability and disease bring about another issue related to the use of PGD. Certain couples prefer their children to have the same condition affecting the parents, thus selection of that embryo can ensure the child will have the desired condition (Cooper & Jungheim, 2010). For example, a couple with dwarfism, recognized as a disability

under the Americans with Disabilities Act of 1990, may undergo PGD with the desire of choosing an embryo that would also have dwarfism, oftentimes reasoning that the disability "culture" will be preserved (Cooper & Jungheim, 2010). Additionally, couples report that relating to the child will be easier if the condition is shared (Cooper & Jungheim, 2010). The selection of a disease or disability for the unborn child is controversial, as one is choosing to give the child a disability instead of "enhancing their life" (Boyle & Savulescu, 2001, pp. 1240-1243; Cooper & Jungheim, 2010).

Preimplantation genetic diagnosis testing for disorders which present in adulthood is less controversial than previously discussed indications because the testing may decrease or eliminate the chance of developing a disorder later in adulthood (Boyle & Savulescu, 2001). Typically, the genetic analysis for adulthood conditions involves screening for specific genes known to be associated with adult onset conditions (Stern, 2014). If the specific gene(s) are present, the embryo will likely not be transferred, depending on the couple's wishes (Boyle & Savulescu, 2001). For example, screening may be completed for Huntington's Disease, BRCA1 and BRCA2, and markers to Alzheimer's disease. If found, the embryo would not be transferred to decrease the possibility of the resulting offspring developing said condition (Stern, 2014). PGD was not widely utilized for adult onset diseases, with Johns Hopkins Public Policy Center reporting 28% of 137 clinics provide such services (Stern, 2014). The ethical controversy surrounding the genetic testing for adult onset disorders is minimal and often combined with PGD use for genetic analysis of Mendelian diseases (Hudson, 2006).

According to Robertson (2003), the use of PGD for Mendelian diseases is typically the least controversial indication, which involves testing of embryos for detrimental diseases, such as cystic fibrosis, Tay-Sachs disease, and sickle-cell anemia. PGD was first utilized experimentally

to eliminate the possibility of inheriting X-linked diseases. The first successful birth after using PGD to identify Mendelian diseases and select a healthy embryo occurred in 1990 (Kamel, 2013). Since then, the use of PGD for Mendelian diseases has continued to increase because ethical controversies regarding this category have remained minimal (Robertson, 2003). Johns Hopkins Institutional Review Board conducted a study in April 2004 and found that 68% of 6,000 participants approved of embryo selection to prevent fatal childhood illness (Hudson, 2006).

Regardless of the indication, PGD presents with an overarching controversy regarding the destruction of embryos. After completing the IVF and PGD process, the remaining embryos may be discarded, frozen for future use, or donated to either research or other couples undergoing IVF (Cooper & Jungheim, 2010). A study conducted by Johns Hopkins Institutional Review Board in April 2004 addressed the ethical issue regarding the point during PGD testing at which the embryo is considered to have "moral worth" (Hudson, 2006, pp. 1638-1645). The survey found that 47% of 6,000 participants stated the point of "moral worth" occurred once the embryo was implanted in the womb. Twenty-six percent stated that the dividing embryo was the point of "moral worth" (Hudson, 2006, pp. 1638-1645). The definition of moral worth and human life of the embryo, concerning the PGD process, continues to be a highly debated issue.

Defining these terms in the process of PGD is particularly difficult (Boyle & Savulescu, 2001; Cooper & Jungheim, 2010). Without a definitive definition of moral worth and human life of the embryo throughout the PGD process, the use of embryos and the actions taken on the remaining embryos after implantation remain a highly debated aspect of PGD (Boyle & Savulescu, 2001; Cooper & Jungheim, 2010).

Each of the possible indications for PGD evokes ethical considerations. The least controversial use of PGD is screening for Mendelian disorders, which reduces the possibility of the embryo having genetic defects. The embryo would not have the detrimental genetic defect upon implantation and growth. Non-Mendelian uses and the destruction of embryos after PGD create more controversy. As mentioned previously, the Non-Mendelian indications include: human leukocyte antigen typing involving the development of embryos for the indication of being a "savior sibling," non-medical sex selection for the implications of gender selection by couple preference, non-medical trait selection involving selection for traits to give the embryo an advantage in life, and selection of embryos for disability and disease ("Nonmendelian disorder," 2002). PGD presents a variety of future reproductive technology applications for Mendelian and Non-Mendelian disorders, and the ethical controversies surrounding each application has yet to be fully understood and discussed.

**Regulation**

Regulation of IVF, PGS, and PGD varies widely from country to country. Based on an IVF Worldwide study (2017), no updated worldwide registry exists with the exact PGD and PGS utilization rate (Weissman et al., 2017). The United States government has minimal regulation or monitoring of the PGD process; however, it does monitor aspects of the PGD process through the U.S. Department of Health and Human Services, Center for Disease Control and Prevention, Food and Drug Administration (FDA), and the Center for Medicare and Medicaid Services (Hudson, 2006, pp. 1638-1645). Of these organizations, the FDA provides regulation of drugs and devices that are utilized in the IVF and PGD process. In addition, "regulation of human tissues for transplantation, facility registration, screen of infectious diseases, record keeping, and the proper handling and storage of tissues" (Hudson, 2006, pp. 1638-1645) is overseen. The

other organizations provide a window of opportunity for the United States government to oversee the processes and provide regulation, if indicated (Hudson, 2006, pp. 1638-1645).

At the state level, each state can regulate the IVF and PGD processes, but few states have implemented laws of this type. Some states have taken a stance on restricting embryos for "research purposes" (Hudson, 2006, pp. 1638-1645). Louisiana prohibits the "intentional destruction of embryos created through IVF" (Hudson, 2006, pp. 1638-1645). Many states have yet to address the regulation of PGD processes, and as a result, there is a lack of understanding of PGD from the general public and healthcare professionals of when and how PGD can be utilized (Hudson, 2006).

**Worldwide Perspectives and Prevalence of Preimplantation Genetic Diagnosis**

A recent web-based survey called, "Preimplantation Genetic Screening (PGS): What is My Opinion?," was conducted in 2015 by IVF Worldwide, which discussed the progression and views of PGS (Weissman et al., 2017). The study evaluated the usage patterns of PGS worldwide to reveal common views and opinions on the topic within the assisted reproductive technology community (Weissman et al., 2017). A web-based survey was sent out to IVF clinical staff across the world, including both user and non-users of PGD, via the website IVF-worldwide.com. The survey prompted results from 386 IVF clinics from 70 different countries and is noted to have one of the highest response rates ever published by IVF-worldwide (Weissman et al., 2017).

According to Weissman et al. (2017), the IVF Worldwide distributed a survey in 2015, which collected data from 386 clinics throughout the world from those who have utilized PGS and non-PGS users who were also IVF Worldwide members. The results showed that 342,600

IVF cycles were performed on a yearly basis and 77% of the responding clinics routinely carried out PGS. Results revealed the top three indications for PGS were maternal age >35 years, patients with a history of repeated implantation failure, and patients who had recurrent pregnancy loss and normal parental karyotype (Weissman et al., 2017). PGS was offered to all patients in only 6% of the clinics (Weissman et al., 2017). Of the clinics that used PGS, PGS was performed in less than 10% of IVF cycles in 47% of those clinics and was used in only 7% of cycles in over 50% of those clinics (Weissman et al., 2017). A portion of respondents stated PGS was not used in their countries due to a lack of technical skill and staffing, low patient demand, cost, or because it was illegal in their country (Weissman et al., 2017). The study analyzed what respondents believed PGS is capable of analyzing/detecting. Seventy-eight percent of respondents believed that PGS can only prevent the transfer of aneuploid embryos, 72% believed it can reduce miscarriage rates, and 60% believed PGS can increase live birth rates (Weissman et al. 2017). Results of this survey emphasize increased interest among the assisted reproductive community for the usage of PGS. Furthermore, the results compiled from 70 countries suggested that physicians and researchers worldwide should share similar guidelines on, and practices of, PGS as no regional specific response correlations revealed (Weissman et al. 2017).

Quinn et al. (2011) conducted a meta-analysis of perceptions of PGD worldwide. The objective of the review was to assess high risk individuals' knowledge and attitudes towards PGD for hereditary cancer. High risk individuals were defined as individuals carrying gene mutations at risk for passing on genetic cancer risk to their offspring (Quinn et al., 2011). A total of 13 studies, published in English from high resource countries worldwide, were combined and analyzed with 4,692 participants involved (Quinn et al., 2011). Overall the results indicated that

35% had no knowledge of PGD and 71% thought PGD should be offered to those affected by considerable risk for hereditary cancers. Of the participants, 50% would personally use PGD if considerable risk for hereditary cancer was a concern. In regard to utilizing PGD to avoid a pregnancy termination, 30% stated PGD should not be utilized. Finally, 33% acknowledged ethical concerns of the PGD process (Quinn et al., 2011). Through this meta-analysis study, the lack of knowledge about PGD, implications for use, and elimination of hereditary diseases is evident, as approximately one third of participants had no knowledge of PGD (Quinn et al., 2011).

**United States' Public Perspectives of Preimplantation Genetic Diagnosis**

A nationwide study called "Public Awareness and Attitudes about Genetic Technology" was conducted in 2002 by The Genetics and Public Policy Center at John Hopkins University. At that time, most Americans approved of using genetic technology for medical purposes but disapproved its use for non-medical sex selection or to select from desirable traits such as intelligence or attractiveness (Princeton Survey Research Associates, 2002). Most people had heard of genetic technologies, but only 24% had heard about PGD (Princeton Survey Research Associates, 2002). This study further revealed that 74% of people approved of PGD to avoid serious genetic disease, 69% approved to ensure the child is a blood match, 60% approved to avoid predisposition diseases such as cancer, 28% approved to choose a child's sex, and 22% approved to select for desirable characteristics of the child (Princeton Survey Research Associates, 2002). Furthermore, 72% approved of IVF, 66% approved of prenatal testing for disease, and 59% approved of genetic engineering to avoid disease (Princeton Survey Research Associates, 2002).

As technology advances within the PGD process, opinions revolving around PGD arise. A 2013 survey, conducted by Harris Interactive Service Bureau (HISB), inspected the US general population's perspectives on PGD. Participants were between the ages of 18 and 75 years old. The HISB cross-sectional study sought to quantify the viewpoints of the public, by surveying a representative population, in respect to age, gender, socioeconomic status, education, race, ethnicity, and religion (Winkelman et al., 2015). Of the 1,006 participants who responded to the survey (94% response rate), motivations for favoring or opposing PGD varied. The majority favored PGD (Winkelman et al., 2015). Support for PGD peaked with considerations toward reducing fatalities early in life (72.9%) and eliminating lifelong disabilities, such as mental retardation or deafness (66.7%) (Winkelman et al., 2015). The most common reasons for favoring PGD included: couples should have reproductive autonomy (75.1 %), "couples should be able to make their own decisions about having a child" (66.2%), and "PGD improves the chances that a couple will have a healthy child" (62.1%) (Winkelman et al., 2015, pp. 665–675). The most common reasons for opposing PGD were: "PGD interferes with nature and places doctors in the role of playing God" (67.7%), "Widespread use of PGD may lead to unforeseen consequences" (46.5%), "PGD leads to the unnecessary destruction of embryos" (45.8 %), "PGD promotes discrimination against people with certain characteristics" (42.3 %), and "There is no regulation of PGD" (22.3%) (Winkelman et al., 2015, pp. 665–675). Participants were more supportive of PGD if they had knowledge of PGD prior to taking the survey (Winkelman et al., 2015). When considering "diseases that may not occur until later in life, such as diseases that place an individual at a high risk for cancer during adulthood," 48% supported screening (Winkelman et al., 2015, pp. 665-675).

With regards to genetically-based trait selection, where does the public draw the line? Favored sex selection was supported by 21% of participants; favored personality traits was supported by 18.9%; favored physical traits were supported by 14.6% of participants (Winkelman et al., 2015). Men were two to three times more supportive of genetically-based trait selection (Winkelman et al., 2015). Winkelman et al. noted, "More research is needed to further understand the different perspectives of men and women in regard to PGD and offspring trait preferences" (2015, pp. 665–675).

As a whole, the 2013 study revealed significant variations in opinion based on gender, race, and education (Winkelman et al., 2015). Asians were four times more likely to support favored sex selection, and African Americans were two times more likely to support sex selection, as compared to Caucasians (Winkelman et al., 2015). Participants with three or more children were significantly less supportive of PGD for genetic diseases (Winkelman et al., 2015). As of 2013, over 80% of United States fertility clinics allowed sex selection (Winkelman et al., 2015). Demographically, 49.5% of participants knew someone with a developmental disorder, 27.7% knew about PGD before taking the survey, and 28.5% of participants knew someone who used assisted reproductive technology to have a healthy pregnancy (Winkelman et al., 2015). In general, participants supported limited applications, despite the widespread availability of genetic screening and sex selection (Winkelman et al., 2015).

**Physicians' Perspectives of Preimplantation Genetic Diagnosis**

A study conducted in 2012 surveyed 220 US internists on their views of the possibility of treating genetic disorders by PGD (Klitzman et al., 2013). The survey in this study asked questions about what diseases warranted PGD (Klitzman et al., 2013). Diseases included hereditary ovarian/breast cancer, cystic fibrosis, Huntington's disease, irritable bowel syndrome,

Duchenne muscular dystrophy, familial retinoblastoma, adenomatous polyposis, and cardiomyopathy, type I diabetes, among others (Klitzman et al., 2013). Results found that many providers would recommend PGD to patients for cystic fibrosis (33.7%), breast cancer (BRCA 23.5%), familial adenomatous polyposis (FAP 20.6%), and familial hypertrophic cardiomyopathy (19.9%). Far fewer were in support of social sex selection (5.2%) (Klitzman et al., 2013). Over 50% were unsure if they would recommend PGD in every disease asked about (Klitzman et al., 2013). Of those surveyed, only 4.9% had suggested PGD to patients and only 7.1% felt they could adequately answer patients' questions regarding the topic (Klitzman et al., 2013).

Approximately half (49.4%) would not recommend PGD to patients for sex selection due to non-medical reasons, and 45.4% were unsure (Klitzman et al., 2013). The study suggests that internists feel they have insufficient knowledge about PGD and many are unsure when to discuss the option with patients, even with genetic disorders such as cystic fibrosis and Duchenne muscular dystrophy, which are more commonly utilizing PGD for detection (Klitzman et al., 2013). For example, 54.3% of internists were uncertain about referring in cases of cystic fibrosis, 56.9% of internists were uncertain about referring in cases of Huntington's disease, 54.9% of internists were uncertain about referring in cases of Duchenne muscular dystrophy. Other diseases and indications discussed with internists include: familial retinoblastoma, familial adenomatous polyposis, familial hypertrophic cardiomyopathy, hereditary breast/ovarian cancer, long QT syndrome, Type I diabetes, inflammatory bowel disease, and sex selection without medical implications, of which internists were uncertain when to refer in 50-60% of cases (Klitzman et al., 2013). This study shines light on the fact that physicians, specifically internists,

need more education and training to fully understand PGD in order to make informed recommendations, referrals, and decisions for PGD testing.

In 2003, a set of qualitative interviews with genetic professionals, pediatricians, and parents in Chicago, Illinois were conducted to evaluate perspectives on genetic testing (Campbell & Ross, 2004). The study focused on evaluating the benefits and risks of predictive genetic screening of young children for genetic links to criminal behavior (Campbell & Ross, 2004). Healthcare professionals largely opposed genetic testing unless treatment was available, and, consequently, opposed genetic screening of young children for genetic links to criminal behavior (Campbell & Ross, 2004). Parents, on the other hand, supported the use of genetic testing even in the absence of treatment, like testing for genetic links to criminal behavior (Campbell & Ross, 2004). Parents focused on environmental influences and changes (Campbell & Ross, 2004). Pediatricians and genetic professionals were concerned with potential harm of parents and children possessing the negative information, which could lead to environmental changes or self-fulfilling prophecies (Campbell & Ross, 2004).

From a United States 2014 survey, attitudes of 163 neurologists and 372 psychiatrists were evaluated (Abbate et al., 2014). Of the respondents, approximately 25% of neurologists and 32% of psychiatrists discussed genetic testing with their patients; however, only 2.9% neurologists or psychiatrists discussed PGD (Abbate et al., 2014). Most psychiatrists and neurologists would refer patients for PGD who were at risk for passing on Huntington's disease, Tay-Sachs, and cystic fibrosis (CF). Specifically, 69.8% of psychiatrists and 59.3% of neurologists would refer patients for PGD for CF (Abbate et al., 2014). For Huntington's disease, 74.7% of psychiatrists and 59.3% of neurologists would refer for PGD (Abbate et al., 2014). Only 11.5% of psychiatrists and 7.6% of neurologists would refer for sex selection

(Abbate et al., 2014). Paralleling the internist study, the majority of providers did not feel knowledgeable for patient referrals or answering questions about PGD due to limited experience with PGD and genetic testing (Abbate et al., 2014).

In a United States 2010 study, only 17% obstetricians/gynecologists respondents felt that they were knowledgeable about PGD (Abbate et al., 2014). When asked what six cancer syndromes (cancer syndromes associated with genetic mutations) can be detected with PGD, only 22% answered correctly (Abbate et al., 2014). Additionally, 43% of obstetricians/gynecologists referred patients with hereditary cancer for PGD (Abbate et al., 2014).

The idea that providers have a lack of knowledge on PGD was supported in a study done in 2016 in Malaysia (Olesen et al., 2016). The study analyzed the perspectives of medical professionals regarding ethical implications and issues pertaining to PGD by interviewing medical professionals working with women or couples in the process of undergoing PGD (Olesen et al., 2016). Through extensive interviewing, the study revealed that 'low health literacy' of patients, described as lack of information and limitations about PGD, contributed to misconceptions, total rejections, and negative attitudes towards PGD and patients who choose to use it (Olesen et al., 2016, para. 1). These findings are consistent with past studies done indicating that "low knowledge of PGD leads to a moderate acceptance of PGD and to a high level of need for information about PGD" (Olesen et al., 2016, para. 20).

**Conclusion**

As technology continues to advance, ethical concerns have inevitably attracted the attention of those favoring and opposing PGD. Consequently, researchers globally have attempted to quantify the opinions and rationale surrounding PGD to gather a consensus. Amidst

the plethora of data points presented in this literature review, a single conclusion emerges: no consensus exists. Generally, research has shown that medical experts are in support of PGD for the medical purposes of avoiding serious and life-threatening genetic diseases but are not as supportive in using PGD for less serious or late onset diseases or sex selection (Olesen et al., 2016). Populations frequently studied were the public and specialty health care providers. However, no studies were found regarding the perspectives on PGD with regards to PAs. The goal of this study is to analyze PAs' approval and disapproval rate of PGD use for Mendelian vs. Non-Mendelian disorders and the common reasons of approval and disapproval of the utilization of PGD, with respect to the Central US and West Coast.

# Chapter 3: Methodology

## Introduction

The purpose of this study was to determine the percentage of PAs that approve and disapprove of PGD use for Mendelian vs. Non-Mendelian disorders along with the common reasons that PAs approve and disapprove of the utilization of PGD. This study attempted to evaluate the following questions:

1. What is the percentage of PAs that approve of PGD use for Mendelian vs. Non-Mendelian disorders?
2. What is the percentage of PAs that disapprove of PGD use for Mendelian vs. Non-Mendelian disorders?
3. What are the most common reasons PAs approve the use of PGD?
4. What are the most common reasons PAs disapprove the use of PGD?

The following sections will outline the methodology and the population of the study. The study design, instrumentation technique, population description, study procedure, data collection and analysis, study validity and reliability, as well as study delimitations and limitations will be described below.

## Study Design

The research was a quantitative study surveying PAs from two different regions within the United States (US), including the Central US and the West Coast. Based on the practicing PA population within each respective region, members of California Academy of Physician Assistants [CAPA (CA)] (>2,801 practicing PAs) and members of Kansas Academy of Physician Assistants [KAPA (KS)] (602-1275 practicing PAs) were surveyed. A survey was used to collect PA perspectives, understandings, and ethical considerations of PGD. As a web-based

survey tool, an email was sent to certified PA members through each states' respective Academy for Physician Assistants with a link to the survey included. A statement of confidentiality and informed consent was included at the beginning of the survey, and no contact or personal information was collected. The survey was open to complete from July 10, 2018 to September 1, 2018. A reminder email was sent to CAPA and KAPA organizations, who then sent a subsequent email to the respective members, every three weeks to improve response rates.

**Materials and Instrumentation**

The research study used a twelve-question survey, modified from a study conducted by Winkelman et. al, which analyzed the public's perspectives on the use of PGD (2015). Permission was obtained from William Winkelman MD, by telephone and confirmed via email (Appendix A) to use and make appropriate changes to the previous survey (Appendix B). Alterations were made to the background information about PGD, due to surveying certified PAs rather than the general public. Additionally, throughout the survey questions the term 'doctor' was substituted with 'provider'. When considering the target population of PAs, non-pertinent demographic questions were excluded. The only demographic question included asked participants for the state in which they practice as a PA. See adapted survey tool in Appendix C.

The first three questions of the survey asked about participants' beliefs regarding PGD use to screen embryos for certain medical conditions or diseases which could be life threatening or cause disability, otherwise considered Mendelian Disorders. Options for answers to the questions were strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. Questions four and five asked participants to select any or all options that pertain to why a participant may agree or disagree with the use of PGD in particular scenarios.

The following section included four questions designed to explore participants' beliefs regarding whether PGD should be used to screen embryos for gender selection, physical characteristics, personality traits, or sexuality, otherwise considered Non-Mendelian traits. The options for answers to the questions were strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. The next question referenced the previous questions' responses. If the participant agreed to the prior questions for the use of PGD to screen embryos for gender selection, physical characteristics, personality traits, or sexuality, the participant was then prompted to select any of the three responses listed pertaining to why they agreed. The following question, if they disagreed to the prior questions, asked participants to select any that apply of the five options listed for why they disagreed with the use of PGD.

Lastly, the survey included a demographic section which asked in which state the participant practices.

The survey in this study was used to collect the following information:

1. Data conveying how many PAs approve the use of PGD for Mendelian disorders.
2. Data conveying reasons why PAs approve the use of PGD for Mendelian disorders.
3. Data conveying how many PAs disapprove the use of PGD for selecting for Non-Mendelian traits.
4. Data conveying reasons why PAs disapprove the use of PGD for selecting for Non-Mendelian traits.

**Study Population**

In order to obtain a large population and formulate generalized statements of the US population in regards to PGD, the study utilized the responses of PAs from one state of the Central US and West Coast regions. The state from each of these regions was chosen from data

collected by the National Commission on Certification of Physician Assistants (NCCPA) in 2016. The data indicated which states within the US had the highest PA population. From this data, California and Kansas, with more than 2,801 practicing PAs in each state, were chosen from the respective regions out of convenience and an attempt to obtain the largest sample size possible.

Responses were obtained from willing participants ages 18 - 75, who were PAs and members of the CAPA and KAPA. Obtaining the responses from PAs of a variety of health systems and specialties was intended to reduce any bias in the data collection. Consent was obtained through email from CAPA's and KAPA's administrators after the executive board approval (Appendix D).

The survey was distributed from July 10, 2018 to September 1, 2018. All survey participants were required to read an informed consent prior to taking the survey. To be included in the study, the participants need to speak English fluently as the survey was created and intended for fluent English participants and no adjustment was in place for non-fluent English-speaking individuals. Additionally, the participants needed to be 18 years of age or older, as parental consent would have been needed for anyone under the age of 18. Demographic information obtained only included state of membership. No personal identifier information was obtained from the participants.

**Procedure**

Consent to utilize the survey was obtained through email prior to sending out the web-based survey to the specific state PA associations. William Winkelman, MD gave consent to utilize, alter, and distribute his survey tool (Appendix A). Alterations to the survey tool were reviewed by research chair, Christina Hanson, PA-C. Additionally, an email was sent to CAPA

and KAPA requesting permission to survey their members to quantify PA perspectives on PGD. Access to CAPA members was requested and granted through Jonathan Kulesza (Appendix D). Access to KAPA members was requested and granted through Douglas Smith (Appendix D). Initially, the survey tool (Appendix C), was emailed to each respective representative from CAPA and KAPA (Appendix D). Secondly, each representative distributed the survey, by email, to their respective Academy of Physician Assistant members. Reminder emails were distributed to Douglas Smith, KAPA representative, and Jonathan Kulesza, CAPA representative, every three weeks until the conclusion of the study (Appendix D). Data was collected using Qualtrics, a web-based research software program, and surveys were initiated with a hyperlink. Participants were presented a statement of confidentiality, informed consent, and a brief explanation of the study's purpose (Appendix E). No contact or personal information was obtained. Data collection from the survey spanned from July 10, 2018 to September 1, 2018. Access to the survey was closed from further participants on September 1, 2018. Data was downloaded on an encrypted, single USB, deleted from Qualtrics server, and stored in a locked, research office at Bethel University Anderson Center, Arden Hills, Minnesota. Raw data, processes, and statistical analysis was stored on the USB. Throughout research analysis, responses were temporarily stored on a password protected computer. Once data analysis was uploaded onto a USB, all survey data and analysis was deleted from the password-protected computer. The encrypted, single USB will be kept for five years, and then destroyed.

**Statistical Analysis**

Data collected from the survey through Qualtrics was downloaded and analyzed. First, the frequency of participants' responses for each question was quantified. Using the Likert scale options for answers to the survey questions, the number of participants that strongly agree, agree,

neither agree nor disagree, disagree, or strongly disagree for each question was quantified. Then using the frequencies, researchers determined the percentage of participants that answered each response of each question. This revealed the percentage of PAs that approve or disapprove of the use of PGD for Mendelian disorders (questions 1-3) and Non-Mendelian traits (questions 6-9). Regarding questions 4, 5, 10, and 11, the responses for the common reason(s) of approval or disapproval of the use of PGD were also quantified and calculated into percentages for representation.

Next, MedCalc statistical software comparison of proportions calculator was used to determine statistical significance for comparing the frequency of approval vs. disapproval responses for each question. For these calculations in each question, strongly agree and agree responses were grouped together and strongly disagree and disagree responses were grouped together. The two groups were then compared to find p-values for each question and whether there was a difference between approval and disapproval of PGD in each medical scenario.

Furthermore, because the responses to questions 1-3 were quite varied, a repeat ANOVA test was done to compare the three questions to determine if participants preferred approval or disapproval of PGD use for a specific Mendelian condition. The repeat test was used to compare the three questions because each participant was asked the same three questions. Responses were scored as the following: strongly agree=5, agree=4, neither agree nor disagree=3, disagree=2, strongly disagree=1. The repeated ANOVA test was done to determine the p-values for comparing each question to another (Table 1).

Physician assistants' perspectives of PGD use, quantified from the survey question results as described above, were then compared to the results of the original Winkelman, et al (2015) survey regarding public perspectives on the use of PGD. The comparison between the

general public perspectives on PGD to that of PAs revealed if there are quantitative differences between the two groups.

**Validity and Reliability**

The researchers performing this study adapted the survey for the use of analyzing the responses from PAs. The original survey tool was formulated by a study conducted by William Winkelman, MD, who specifically had the survey tool catered to surveying physicians' and the general public's understandings, perspectives, and ethical considerations of PGD. The original survey was completed by 1,006 participants who were members of the Harris Interactive Service Bureau (HISB). The respondents were selected to participate to provide representation based on sex, education, race/ethnicity, geography, religion, and income. Additionally, the participants of the survey had to be U.S. residents aged 18 - 75 years. The original study was approved by the Human Research Committee of Brigham and Women's Hospital prior to distribution.

Utilizing the questions of a previously published study in a peer reviewed journal, completed by 1,006 participants, added to the validity and reliability of this study's survey. Validity of the survey tool was ensured from the review by the Human Research Committee of Brigham and Women's Hospital prior to distribution, providing basic information of PGD to participants prior to completing the survey, and limiting the responses available to the participants. Reliability was also ensured by all participants completing the exact same survey, thus, all participants received the same background information about PGD and read and completed the exact same survey questions.

The adapted survey included basic information about PGD, thus all the participants had a basic understanding prior to completing the survey. Validity was confirmed when asking questions relevant to the understandings, ethical considerations, and perspectives about PGD,

which had been previously utilized in Dr. William Winkelman's survey tool. After each question, the participant had four to five response options depending on the question. The reliability of the study was determined by making the survey questions precise and consistent by having "strongly agree/agree/neither agree nor disagree/disagree/strongly disagree" for many of the responses. Thus, the responses of the survey were those of the participant and specifically the participant's opinion about PGD.

The same survey was utilized when collecting the responses from all participants, which ensured the study is reliable throughout the study population. Lastly, the survey tool was reviewed by an expert panel consisting of four Minnesota practicing PAs, reviewing the survey tool for relevance and validity to the intended population.

**Limitations and Delimitations**

The survey in this study was sent out to members of CAPA and KAPA. The response rate was dictated by recipients' decision to either participate or not participate. The willingness to participate in this survey may have been influenced by recipients' previous knowledge or interest about the topic. Variables such as exposure to PGD, religious environment, and cultural environment varying by region may have influenced trends in perspectives. Due to the controversial nature of PGD, the resultant data may have been skewed by subsequent response bias by those who choose to participate. The participants may have been influenced by societal pressures or expectant responses and answered questions misleadingly or untruthfully. Not all practicing PAs in California or Kansas are members of their respective Academy, which lowered the number of PAs who received the survey, thus lowering the potential response rate. CAPA had a 50% membership of practicing PAs within the state. KAPA had a 13% membership of practicing PAs within the state.

Additionally, using CAPA and KAPA as a distributor of the survey may have limited the comprehensiveness of the research, as not all PAs practicing in these states are members of CAPA and KAPA. The survey only reached a portion of PAs in the states where the survey was distributed, therefore, results do not encompass all PAs across the entire US. Another limitation of utilizing CAPA and KAPA is that the researchers were not able to randomize the participants of the survey. Subsequently, the participants were compiled of those who chose to participate only and were members of their respective academy.

Notable de-limitations imposed by the researchers include selection bias based on the regions where the survey was distributed. For the purpose of this study, CAPA and KAPA were utilized to distribute the survey to one state in each the Central US and West Coast regions. The selection of two states was due to three reasons: striving to survey states with the highest PA population in the Central US and West Coast regions according to NCCPA 2016 data, the impractical and limited nature of obtaining information from PAs from every US state, and striving to obtain a broad view of the approval and disapproval rates of PGD use for Mendelian vs. Non-Mendelian disorders/the common reasons of approval and disapproval of PGD use of PAs across the US. Only two states were selected to survey, which limited the sample size allowing for a manageable data set for analysis.

Utilizing a survey for the basis of the research is another de-limitation imposed by the researchers. Respondents answers may have been influenced by survey format, wording of questions, or answer options, thus influencing survey results.

**Conclusion**

The research methodology involved emailing a survey to members of CAPA and KAPA to collect data about the percentage of PAs that approve and disapprove of PGD use for

Mendelian vs. Non-Mendelian disorders and the common reasons that PAs approve and disapprove of the utilization of PGD. The results of the survey are relevant due to the increase in practicing PAs and an increase in PGD utilization in reproductive technology. As PGD becomes more prevalent in reproductive technology, assessing PAs' approval and disapproval rates of PGD use for Mendelian vs. Non-Mendelian disorders and the common reasons of approval and disapproval of PGD becomes crucial in providing optimal care to patients. Chapter 4 will analyze the results of the surveys by quantifying responses to the survey questions. Chapter 5 will contain research limitations and analysis of conclusions made from the quantitative results. Lastly, Chapter 5 will include discussion for possibilities of future research.

## Chapter 4: Results

Data collection occurred from July 10, 2018 until September 1, 2018, yielding a response of 15 respondents. Survey was open to Kansas Academy of Physician Assistants and California Academy of Physician Assistants. Fifteen total participants started the electronic survey, with 14 participants completing the survey. All 14 participants completing the survey were from KAPA. No responses were obtained from CAPA.

After downloading data responses from Qualtrics, all eleven questions were evaluated with respect to PGD perceptions, understandings, and ethical considerations. Frequency of responses were obtained and raw percentages were calculated. Comparisons were made between strongly agree/agree groups vs strongly disagree/disagree groups for each question 1-3 and 6-9. Comparisons were also made between responses to Mendelian condition questions 1-3.

First, the grounds on which PGD should or should not be performed by providers were quantified for Mendelian conditions, with respect to: diseases fatal early in life, diseases that cause lifelong disability such as mental retardation or deafness, and diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood (*Figure 1*).

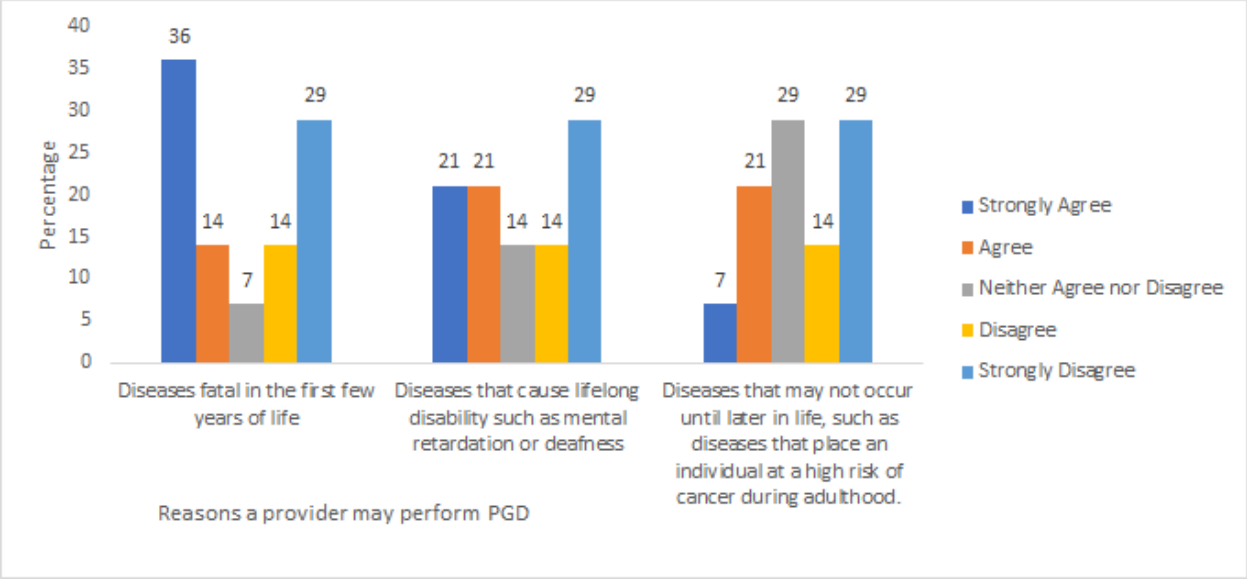


*Figure 1*. Percentage of KAPA Physician Assistants who strongly agreed, agreed, neither agreed nor disagreed, disagreed, and strongly disagreed PGD should be used for Mendelian conditions: diseases fatal in the first few years of life, diseases that cause lifelong disability such as mental retardation or deafness, and diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood (n=14).

Perspectives from KAPA Physician Assistants were mixed. When screening for diseases fatal early in life, 50% of participants agreed or strongly agreed with the use of PGD, 43% disagreed or strongly disagreed, and 7% neither agreed nor disagreed to the use of PGD. There was no statistical significance for agree/strongly agree vs disagree/strongly disagree groups (p=0.72). When screening for diseases that cause lifelong disability such as mental retardation or deafness, 43% of participants agreed or strongly agreed in the use of PGD, 43% disagreed or strongly disagreed, and 14% neither agreed nor disagreed. Finally, when screening for diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood, 29% of participants agreed or strongly agreed with the use of PGD, 43% of participants disagreed or strongly disagreed, and 29% neither agreed nor disagreed in the use of PGD. There was no statistical significance between agree/strongly agree vs disagree/strongly disagree groups (p=0.45).

Those who agreed or strongly agreed to using PGD for screening did so most often on the grounds of: PGD improving the chances that a couple will have a healthy child (43%, n=7) and that couples should be able to make their own decisions about having a child (57%). One participant did so on the grounds that PGD can eliminate certain genetic diseases forever (14%). Those who disagreed or strongly disagreed to using PGD for screening did so most often on the grounds of: PGD interfering with nature and places providers in the role of "Playing God" (71%, n=7), and PGD promoting discrimination against people with certain diseases (29%).

Next, because the responses to questions 1-3 were quite varied, responses of these questions were scored and compared to determine if participants preferred approval or disapproval for the use of PGD for any of the following situations: 1) diseases fatal in the first few years of life, 2) diseases that cause lifelong disability such as mental retardation or deafness, and 3) diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood. Analysis showed no statistical significance between the three situations (see Table 1 p-values for each comparison situation). All p-values were >0.05.

Table 1

*Pairwise Comparisons for Responses to Mendelian Conditions Regarding PGD approval or disapproval*

| Mendelian conditions compared for the use of PGD | | | Mean difference | Std. Error | P [a] | 95% CI [a] |
|---|---|---|---|---|---|---|
| Diseases fatal in the first few years of life | - | later in life | 0.5 | 0.203 | 0.0855 | -0.0574 to 1.057 |
| | - | lifelong disability | 0.214 | 0.114 | 0.2468 | -0.0982 to 0.527 |
| Diseases that occur later in life | - | 1st few years of life | -0.5 | 0.203 | 0.0855 | -1.057 to 0.0574 |
| | - | lifelong disability | -0.286 | 0.163 | 0.3116 | -0.734 to 0.163 |
| Diseases the cause lifelong disability | - | 1st few years of life | -0.214 | 0.114 | 0.2468 | -0.527 to 0.0982 |
| | - | later in life | 0.286 | 0.163 | 0.3116 | -0.163 to 0.734 |

Results of a repeated ANOVA test to compare the responses to questions 1, 2, and 3. Data was scored as the following: strongly agree=5, agree=4, neither agree nor disagree=3, disagree=2, strongly disagree=1. P-values reveal no statistical significance when comparing approval rates for Mendelian conditions.

Second, the grounds on which PGD should or should not be performed by providers were quantified for Non-Mendelian traits, with respect to: sex selection, physical characteristics such as height, eye color, or athleticism, personality traits such as intelligence or aggression, and for sexual orientation such as homosexuality (*Figure 2*).

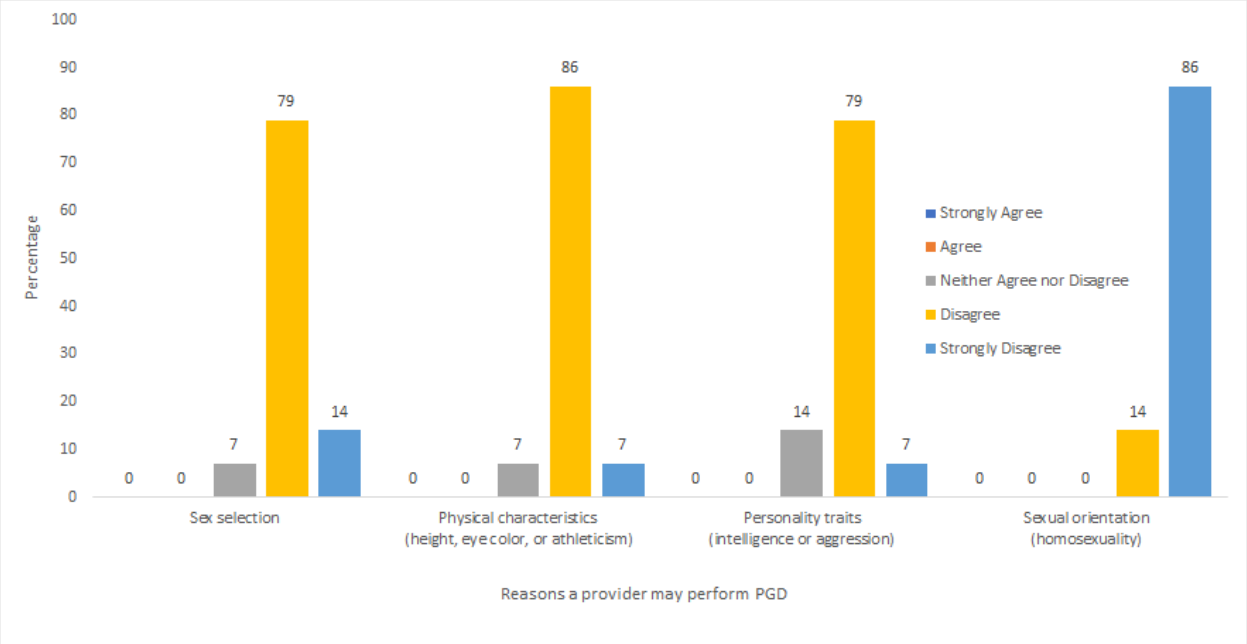


*Figure 2.* Percentage of KAPA Physician Assistants who strongly agreed, agreed, neither agreed nor disagreed, disagreed, and strongly disagreed PGD should be used for Non-Mendelian traits: sex selection, physical characteristics such as height, eye color, or athleticism, personality traits such as intelligence or aggression, and for sexual orientation such as homosexuality (n=14).

With regards to sex selection, 93% of participants disagreed or strongly disagreed to the use of PGD. Likewise, with regards to screening for physical characteristics such as height, eye color, or athleticism, 93% of participants disagreed or strongly disagreed to the use of PGD. When considering screening for personality traits such as intelligence or aggression, 86% of participants disagreed or strongly disagreed to the use of PGD. The majority of participants (86%) strongly disagreed to screening for sexual orientation such as homosexuality with PGD, with two participants who disagreed to the use of PGD (14%). When comparing strongly agree/agree vs strongly disagree/disagree groups in each of the four questions, there is a statistically significant difference for each question $p<0.0001$, considering there were zero participants who agreed or strongly agreed for all questions.

Those who neither agreed nor disagreed to the use of PGD for sex selection, physical characteristics, personality traits, and for sexual orientation did so on the grounds that couples

should be able to make their own decisions about having a child (100%, n=2). Those who disagreed or strongly disagreed to the use of PGD for sex selection, physical characteristics, personality traits, and for sexual orientation did so on the grounds most often because PGD promotes discrimination against people with certain characteristics (46%, n=13). Other considerations included: PGD interferes with nature and places providers in the role of "playing God" (31%), widespread use of PGD may lead to unforeseen consequences (15%), and PGD leads to unnecessary destruction of embryos (8%).

# Chapter 5: Discussion

## Summary of Results

The purpose of this study was to analyze the PA approval and disapproval of the use of PGD based on the survey results. Due to the survey response rate of 14, of which were all from KAPA, results were inconclusive. Through statistical analysis, it was determined that in order to potentially detect a statistical significance in data, power of detection would need to be increased to 80%, and in order to do so, sample size would need to be between 32-45 participants. One conclusion that can be drawn, is the fact that perspectives on PGD utilization amongst KAPA members who responded to the online survey are varied.

When looking at the data, even despite the low response rate, subtle trends may exist. No conclusive indication of whether PGD should be utilized for Mendelian conditions was detected. Regarding opinions on PGD use for diseases in the first few years of life, the results were split almost fifty-fifty, with 50% of participants agreeing/strongly agreeing, 43% disagreeing/strongly disagreeing, and 7% who neither agreed nor disagreed to the use of PGD. This discourse continues for subsequent topics as well. Responses for screening for diseases that cause lifelong disability such as mental retardation or deafness were also split, with 43% of participants agreeing/strongly agreeing in the use of PGD while 43% disagreed or strongly disagreed. Screening for diseases that may not occur until later in life also yielded mixed results, with 29% of participants agreeing/strongly agreeing in the use of PGD and 43% of participants disagreeing/strongly disagreeing in the use of PGD.

The common reasons KAPA members approved of the use of PGD did so on the grounds of PGD improving the chance of the couple having a healthy child, and that the couple should be able to make their own medical decisions about having a child. A further explanation for these

common reasons chosen is as follows. When looking at the options available in the reproductive realm, utilizing PGD to improve the chance of having a healthy child and being able to make these decisions independently is becoming increasingly common. From a medical standpoint, the patient has the choice to complete testing and procedures. The PGD process is a laboratory test completed on DNA of an embryo. Therefore, the choice to complete PGD testing should be up to the couple, and the couple should be able to make their own medical decisions about having that child.

The common reasons KAPA members disapproved of the use of PGD for Mendelian conditions were due to believing PGD interferes with nature and placing providers in the role of "playing God." These commonly cited reasons of PGD use disapproval is not particularly surprising, as they address core, controversial ethical considerations surrounding PGD. The use of PGD can be viewed as "playing God," as the doctors are analyzing the embryos to choose the embryo without particular diseases or conditions. Utilizing the PGD process may eliminate certain diseases that could lead to death or detrimental conditions. Utilizing PGD may also be perceived as manipulating genetics in an omniscient, authoritative manner. Another viewpoint of utilizing PGD can be viewed as eliminating certain communities such as the deaf community.

On the second half of the survey, a shift in responses occurred. When considering PGD for more exclusively non-Mendelian genetic traits, such as sex selection, physical characteristics such as height, eye color, or athleticism, personality traits such as intelligence or aggression, and for sexual orientation such as homosexuality, participants predominantly disagreed with PGD use. No participants agreed or strongly agreed in the use of PGD for sex selection, physical characteristics, personality traits, and for sexual orientation. The majority of participants

disagreed or strongly disagreed with the use of PGD under such trait conditions, and only a couple participants neither agreed nor disagreed.

One might argue a consensus within this survey was reached. However, the reasons participants made the stance of disagreeing on the use of PGD for sex selection, physical characteristics, personality traits, and sexual orientation were quite varied. For example, the most commonly cited reason for disagreeing with PGD use was supported by less than half (46%) of participants, doing so because PGD promotes discrimination against people with certain characteristics. Other responses ranged from PGD interfering with nature and places providers in the role of "playing God" (31%), widespread use of PGD may lead to unforeseen consequences (15%), and PGD leads to unnecessary destruction of embryos (8%).

Regarding the direct comparison between this study and the 2013 study completed by Dr. William Winkelman, significant conclusions cannot be drawn due to the lack of responses of this study. Overall, the 2013 survey that analyzed the US general population's perspectives on PGD indicated that the majority favored PGD (Winkelman et al., 2015). Support for PGD peaked with considerations toward reducing fatalities early in life (72.9%) and eliminating lifelong disabilities, such as mental retardation or deafness (66.7%) (Winkelman et al., 2015). This study had mixed responses on the support of PGD with roughly 50% of KAPA members supporting PGD use for screening for diseases fatal early in life and screening for diseases that cause lifelong disability such as mental retardation or deafness. The support for PGD use dropped slightly to 29% when screening for diseases that may not occur until later in life. Initially, it may appear that the general public and KAPA members support the use of PGD for prevention of diseases, conditions such as mental retardation or deafness, or screening for diseases that present later in life; however, roughly 40% of KAPA members disagreed with the

use of PGD for screening early life diseases and conditions such as mental retardation or deafness. In screening for diseases that present later in life, roughly 40% disagreed with the use of PGD. In comparison, the general public tends to have a more supportive stance on the use of PGD than the KAPA members surveyed in this study.

Common reasons KAPA members supported the use of PGD did so on the grounds of PGD improving the chances that a couple will have a healthy child and that couples should be able to make their own decisions about having a child. In the study completed by Dr. William Winkelman, the most common reasons included: couples should have reproductive autonomy, "couples should be able to make their own decisions about having a child", and "PGD improves the chances that a couple will have a healthy child" (Winkelman et al., 2015, pp. 665–675). The KAPA members and the general public both have a high percentage agreeing with the use of PGD for improving the chances of the couple having a healthy child, and the couple being able to make their own decisions about having a child.

Those that disagreed with the use of PGD did so on the grounds that it would be interfering with nature and be considered "playing God." Similarly, the general public opposed the use of PGD on the grounds that "PGD interferes with nature and places doctors in the role of playing God." In comparison with the use of PGD for analysis of physical characteristics and sex selection, the majority of KAPA members did not support the use of PGD for such a process. Similarly, the general public had a low percentage supporting the use of PGD for sex selection or physical characteristics selection. When considering the study conducted by John Hopkins Institutional Review Board in April 2004, it was found that 72% of 6,000 participants disapprove of utilizing PGD testing for non-medically related traits (Hudson, 2006).

**Limitations and Delimitations**

A limited number of PA academies were targeted for distribution of the study's survey, a factor imposed by the researchers. For the purpose of this study, academies from the East Coast, Central US, and West Coast were chosen based on population of practicing PAs within the state. Three state academies were chosen to collect data and make a generalized analysis of US PA approval and disapproval of the use of PGD. Additionally, three state academies were chosen to limit the data responses for analysis. California (CAPA), Kansas (KAPA), and Virginia (VAPA) were chosen and agreed to participate in the study.

During the initial distribution of the survey, due to administrative changes, VAPA was no longer able to distribute the survey for this study. As a result, the distribution of the survey was further limited and generalized statements about the US PAs approval and disapproval of the use of PGD cannot be made. CAPA and KAPA participated in the distribution of the survey, therefore, data analysis and statements were anticipated to be made about the Central US and West Coast. Zero CAPA members participated in the survey, therefore no analysis could be done for the West Coast.

The use of the survey for this study did not encompass all possible reasons for PGD use or all of the approval or disapproval reasons one might have. The survey was utilized as a tool to further narrow the possible responses and data collected. The use of a web-based survey tool limited the distribution to those practicing with the respective states and members of the respective academies. The online survey also limited the distribution to those that regularly check their Academy's website or emails.

In addition to the limited distribution of the survey to CAPA and KAPA, the sample size of participants was less than anticipated. The study received 15 responses with only 14

participants completing the entire survey. Factors that may have influenced participation may have been due to not all PAs being members of their states respective academies, the lack of face to face contact between the researchers and survey participants, the method of delivery of the survey to the PAs, and lastly, the individual distributing the survey to the PA members or the participants themselves may have held a bias towards the topic being studied.

Face to face interaction may have increased the PA response to the survey, as the PAs would have received the information about the survey and would have been able to complete the survey in person. The lack of face to face contact may have influenced the response rate, especially when considering each academy delivered the survey link and information differently. Modality of survey distribution differed between CAPA and KAPA, with CAPA posting the survey link on the CAPA website and KAPA emailing the link to their members. As a result, the awareness about the survey, including ease of access to the survey, may have impacted the response rate.

The controversial nature of PGD use may have influenced the distribution of the survey, further impacting the response rate. The contact person for each academy may have influenced the response rate to the survey by having a bias about the subject matter. In addition, CAPA and KAPA members' basic foundation of knowledge and personal discrepancies about PGD may have influenced their motivation to participate in this study. Lastly, when completing the survey, the responses of the participants may have been dishonest. When considering the various confounding variables, the results, therefore, may not have accurately reflected PA's approval or disapproval of the use of PGD.

**Further Research**

Investigating perspectives about PGD in the medical community addresses an important topic. With regards to addressing PAs' understanding and stance on indications for PGD use, this study provided a sliver of insight into where KAPA members stand on the issue. Results of the study showed vague generalizations in which participants tended to agree with the use of PGD for Mendelian conditions such as genetic diseases, and tended to disagree with the use of PGD for non-Mendelian genetic traits such as physical characteristics. When considering the low survey response rate, there lies quite a bit of room for improvement in future research. As advancements in genetics will continue to make strides forward, PGD is likely to become more prevalent in practice. Thus, the topic of this study will be important to continue researching to stay updated on providers' perspectives of PGD. Knowing provider perspectives on PGD is important for patient care and considering how providers may be discussing PGD with their patients. Learning more about provider perspectives on PGD will also be helpful in analyzing where providers would benefit from further education about PGD and genetic medicine in general in order to educate their patients effectively.

The simplest, and perhaps most important factor to improve further research for this study is to increase the sample size of the survey participants. A response rate of fourteen is certainly not enough for statistical significance. While it offers a glimpse of current PA perspectives on PGD use, a greater sample size would enable a more conclusive and nuanced understanding on the population, as a whole. Future researchers could attempt to expand the survey population by targeting PAs across the country in different ways, not simply through state PA academies. For example, increasing the sample size could be done through using different distribution techniques for the survey such as emailing or mailing the survey directly to PAs, or

by using face to face contact with PAs to distribute and collect a hard copy of the survey. Researchers could seek out PAs to complete the survey in their workplace or possibly at conferences through the national or state PA associations.

Future research could further examine factors such as participants' detailed background demographics, prior knowledge of PGD, experience with PGD, if they have children, if they know anyone with genetic disabilities, etc. and examine correlation with those factors and their respective perspectives on PGD use. Additionally, future research could investigate how gender plays a role into participants' opinions towards PGD. For example, Winkelman's study found that men were two to three times more supportive of genetically-based trait selection (Winkelman et al., 2015). Winkelman et al. noted, "More research is needed to further understand the different perspectives of men and women in regard to PGD and offspring trait preferences" (2015, pp. 665–675). The relationships between additional factors asked and participants' answers could open up avenues to learning about how one's background and personal life affects their perspectives towards the use of PGD in medical practice.

Additionally, future research could explore further into the reasons why PAs may agree or disagree with the use of PGD. The survey in this study listed only three to four options to choose from as to why the participant may agree or disagree with PGD under certain circumstances, when in reality, reasoning behind such opinions could be abundant. Responses varied greatly, making it difficult to draw conclusions. In the future, it could be interesting for participants to answer open-ended questions in a qualitative setting to get a better idea of reasons why PAs agree or disagree with PGD use.

Finally, another suggestion for future research around the topic of PA perspectives on PGD would be to conduct a qualitative study, as opposed to quantitative. Researchers could

interview PAs to study their attitudes toward PGD and reasons why they may agree or disagree with the use of PGD. Interviews could allow for open ended questions and responses, creating broader results and explanations. Participants may be more honest and variant in their answers and give insight into their perspectives beyond the condensed survey question answers.

**Conclusion**

The purpose of this study was to assess physician assistant approval and disapproval of PGD for Mendelian vs. Non-Mendelian disorders. Additionally, the survey aimed to explore common reasons why PAs approve or disapprove of PGD utilization. A 12-question survey was sent to CAPA members through a link posted on their organization website and to KAPA members through their email. A total of 14 surveys were completed by PAs who are members of KAPA and practicing in Kansas. Data revealed no statistical significance between approval and disapproval of PGD for Mendelian conditions as responses were varied. Regarding PGD approval and disapproval for Non-Mendelian traits, data revealed statistical significance due to the fact that all participants responded with disagree or had no opinion.

In general, trends from the results showed that participants most commonly approved of PGD utilization to screen for diseases that are fatal in the first few years of life. Most commonly, participants agreed to PGD use on the basis that couples should be able to make their own decisions about having a child. Overall trends for opinions on PGD for Mendelian conditions cannot be concluded as responses were variable. Participants primarily disapproved of, with a couple having had no opinion for PGD utilization for Non-Mendelian traits including gender selection, physical characteristics, personality traits, or sexuality. The most common reason participants disagreed with using PGD for such screening was the belief that PGD interferes with nature and places providers in the role of "playing God." Limitations and

delimitations of the study included the limited population size, distribution methods of the survey, narrow survey questions and answers, PA association members and participants' knowledge and opinions towards PGD, and the fact that PGD is controversial topic.

The significance of this research does not lie in impressive statistics nor astounding sample size numbers. Rather, this research serves as opening the door to potential avenues of future research. With respect to advancements in genetic medicine, PGD will likely become more popular and more prevalent within medicine. PAs should know how to address PGD use in patient care, and be able to refer patients to the right provider if they are uncomfortable or unable to offer their patients appropriate care and professional perspectives surrounding PGD. It can be concluded that a variety of opinions surround PGD use. Providers need to be educated on PGD use, and respect their patients' wishes and healthcare needs. Future research could shed light on to where PAs need further education about genetics and PGD, enabling positive growth in the future of medicine.

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# APPENDIX A

Permission from William D. Winkelman, MD

Written Permission from Dr. William D. Winkelman

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

**Survey Request from Public perspectives on the use of PGD**

2 messages

**Samantha Hamlin** <sah68693@bethel.edu> Wed, Nov 1, 2017 at 11:18 AM
To: william.winkelman@mah.org

Good morning from Minnesota,

Thank you for chatting, as discussed over the phone: I am currently a physician assistant student at the Bethel PA Program in Arden Hills, Minnesota. A group of two other students and myself are conducting research on the physician assistant perspectives on the use of PGD. We found your article to be a valuable asset in our research.

May we have permission to use and edit your questionnaire in conducting further research for our project?

Thank you,
Samantha Hamlin
Sarah Barnes
Claire Johnson

**Winkelman, William** <William.Winkelman@mah.org> Wed, Nov 1, 2017 at 11:26 AM
To: Samantha Hamlin <sah68693@bethel.edu>

Good luck with the study. You're more than welcome to use my questionnaire in your project.

-Will

William D. Winkelman, M.D.
Clinical Fellow, Female Pelvic Medicine and Reconstructive Surgery
Mount Auburn Hospital / Beth Israel Deaconess Medical Center / Harvard Medical School
Cell: 917-733-2125
Pager: 617-339-5287
Email: William.Winkelman@mah.org

**From:** Samantha Hamlin <sah68693@bethel.edu>
**Sent:** Wednesday, November 1, 2017 12:18 PM
**To:** Winkelman, William
**Subject:** Survey Request from Public perspectives on the use of PGD

[Quoted text hidden]

# APPENDIX B

William Winkelman, M.D. Survey Tool

# Dr. William Winkelman's Survey Tool

*Section 1*

When a woman's egg and a man's sperm join, they form a fertilized egg which then grows into an embryo and can eventually lead to a pregnancy. This part of the survey asks you your opinions on whether doctors should provide genetic diagnosis of human embryos before pregnancy.

Preimplantation genetic diagnosis, or "PGD" is a procedure that takes place in a lab with test tubes and can be used to identify specific diseases in embryos before a woman gets pregnant. PGD can detect diseases that are fatal in the first few years of life as well as diseases that can cause significant disabilities throughout a person's life. Patients who decide to undergo PGD must first agree to undergo in vitro fertilization where the woman's egg and the man's sperm are combined outside the human body in order to form a fertilized egg which then grows into an embryo. In PGD, one or two cells from an embryo are removed and tested for various diseases. If a specific disease is identified then the embryo is discarded. If there is no identified disease then the embryo is placed in the woman's uterus with the ultimate goal of a healthy baby.

Questions

In the following questions, please indicate the answer that best reflects your own personal beliefs. There is no right or wrong answer.

1. Doctors should be able to perform PGD to screen for diseases that are fatal in the first few years of life.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree
2. Doctors should be able to perform PGD to screen for diseases that cause lifelong disability such as mental retardation or deafness.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree
3. Doctors should be able to perform PGD to screen for diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

4. If you "agree" or "strongly agree" to questions 2, 3 or 4 that doctors should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)
    a. Couples should be able to make their own decisions about having a child
    b. PGD improves the chances that a couple will have a healthy child
    c. PGD will lower healthcare costs and may result in a better society
    d. PGD can eliminate certain genetic diseases forever
    e. Other, please specify:
    f. _____
5. If you "disagree" or "strongly disagree" to questions 2, 3 or 4 that doctors should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)
    a. PGD leads to the unnecessary destruction of embryos
    b. PGD promotes discrimination against people with certain diseases
    c. PGD interferes with nature and places doctors in the role of "playing God"
    d. Widespread use of PGD may lead to unforeseen consequences
    e. There is no regulation of PGD
    f. Other, please specify:
    g. _____

Additional background information for participants

While PGD is a procedure that is most commonly used to identify diseases, in the future it potentially could be used to test for physical characteristics, personality traits, abilities, or sexual orientation. Again, please indicate the answer that best reflects your own personal beliefs. There is no right or wrong answer.

6. Doctors should be able to perform PGD for sex selection
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

7. Doctors should be able to perform PGD to screen for physical characteristics such as height, eye color or athleticism.
    f. Strongly agree
    g. Agree
    h. Neither agree nor disagree
    i. Disagree
    j. Strongly disagree

8. Doctors should be able to perform PGD to screen for personality traits such as intelligence or aggression.
    k. Strongly agree
    l. Agree
    m. Neither agree nor disagree
    n. Disagree
    o. Strongly disagree

9. Doctors should be able to perform PGD to screen for sexual orientation such as homosexuality
    p. Strongly agree
    q. Agree
    r. Neither agree nor disagree
    s. Disagree
    t. Strongly disagree

10. If you "agree" or "strongly agree" to questions 7, 8, 9 or 10 that doctors should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)
    u. Couples should be able to make their own decisions about having a child
    v. Selecting ideal traits will help a child lead a successful life
    w. Selecting ideal traits will result in a better society
    x. Other, please specify:
    y. _____

11. If you "disagree" or "strongly disagree" to questions 7, 8, 9 or 10 that doctors should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)

    z. PGD leads to the unnecessary destruction of embryos
    aa. PGD promotes discrimination against people with certain characteristics
    bb. PGD interferes with nature and places doctors in the role of "playing God"
    cc. Widespread use of PGD may lead to unforeseen consequences
    dd. There is no regulation of PGD
    ee. Other, please specify:
    ff. _____

*Section 2*

This section asks you for some basic background information. This information is for research reasons only. It will not be used to identify you in any way.

For each of the following questions, please select the answer that best describes you

1. What is your gender?
    a. Male
    b. Female
2. What is your age?
    a. (Numerical values from 18 to 75)
3. What is your ethnicity?
    a. Hispanic or Latino
    b. Not Hispanic or Latino
4. What is your race? (select all that apply)
    a. American Indian or Alaska Native
    b. Asian

   c. Black or African American
   d. Native Hawaiian or Pacific Islander
   e. White
   f. Other
5. In which state do you live?
   a. (*Dropdown menu of all 50 states*)
6. What is your approximate household income?
   a. $20,000 or less
   b. $20,000–$40,000
   c. $40,001–$60,000
   d. $60,001–$80,000
   e. More than $80,000
7. What is your religion?
   a. Christian – Protestant
   b. Christian – Catholic
   c. Jewish
   d. Muslim
   e. Hindu
   f. Atheist/Agnostic
   g. Other, please specify:
   h. ___
8. Which of the following best describes your level of education?
   a. Some high school or less
   b. High school diploma or GED
   c. Some college
   d. College degree
   e. Some graduate school
   f. Graduate or professional degree
9. Prior to this study have you ever heard of preimplantation genetic diagnosis (PGD)?
   a. Yes
   b. No
10. Do you personally know anyone with a genetic or developmental disorder?
    a. Yes
    b. No
11. Do you personally know anyone who required the help of assisted reproductive technology to achieve a healthy pregnancy?
    a. Yes
    b. No
12. How many biological children do you have?
    a. 0
    b. 1
    c. 2
    d. 3
    e. 4
    f. More than 4

Thank you for taking the time to participate in our study.

# APPENDIX C

## Current Researcher's Adapted Survey Tool

# Current Researcher's Adapted Survey Tool

Informed Consent:

You are invited to participate in a study that is being conducted by Minnesota Physician Assistant Students from Bethel University's Physician Assistant Program, which is a partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. The purpose of the study is to analyze the understandings, perspectives, and ethical considerations physician assistants hold in relation to preimplantation genetic diagnosis (PGD). You were selected as a possible participant in this study because you are a physician assistant practicing in California, Kansas, or Virginia.

Participation in the study is voluntary. If you decide to participate, participation involves a short, 10-minute online survey adapted by researchers from Bethel University's PA Program. The survey questions will ask about your understanding, utilization, and ethical implications of PGD. If you feel uncomfortable in any way during the online survey, you have the right to skip the question or discontinue the survey with no penalty.

No identifying information will be collected, and data will be stored on an encrypted flashdrive and locked in a Bethel University Graduate Studies staff's office. In any written reports or publications, only aggregate data will be presented, in order to maintain anonymity. Your decision whether or not to participate will not affect your future relations with Bethel University, CAPA, KAPA, or VAPA in any way.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research related injury, please call the contacts listed below. If you so choose, a copy of this informed consent can be offered to you to keep.

We understand that you have an extremely busy schedule and your time is limited. The information that you provide is essential to the validity of this study. Thank you in advance for your participation in this study. If you have any questions, please contact Research Chair: Christina Hanson PA-C, 651-635-8042, Research Committee Member: Jeanne Szarzynski, 651-635-8002, Researcher: Sarah Barnes, 952-843-8696, Researcher: Samantha Hamlin, 507-440-0551, Researcher: Claire Johnson, 612-280-1282.

By continuing with the survey, you have read the information that is provided above, and you are granting consent to participate in this research. Thank you again for your help.

Section 1

Background information: When a woman's egg and a man's sperm join, they form a fertilized egg which then grows into an embryo and can eventually lead to a pregnancy. This part of the survey asks you your opinions on whether providers should provide genetic diagnosis of human embryos before pregnancy.

Preimplantation genetic diagnosis, or "PGD" is a procedure that takes place in a laboratory, where testing is conducted to identify specific diseases in embryos before implantation. PGD can detect diseases that are fatal in the first few years of life as well as diseases that can cause significant disabilities throughout a person's life. Patients who decide to undergo PGD must first agree to undergo in vitro fertilization. In PGD, one or two cells from an embryo are removed and tested for various diseases. If a specific disease is identified then the embryo is discarded. If there is no identified disease then the embryo is implanted.

In the following questions, please indicate the answer that best reflects your own personal beliefs. There is no right or wrong answer.

1. Providers should be able to perform PGD to screen for diseases that are fatal in the first few years of life.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

2. Providers should be able to perform PGD to screen for diseases that cause lifelong disability such as mental retardation or deafness.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

3. Providers should be able to perform PGD to screen for diseases that may not occur until later in life, such as diseases that place an individual at a high risk of cancer during adulthood.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree
4. If you "agree" or "strongly agree" to questions 1, 2, or 3 that providers should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)

a. Couples should be able to make their own decisions about having a child
b. PGD improves the chances that a couple will have a healthy child
c. PGD will lower healthcare costs and may result in a better society
d. PGD can eliminate certain genetic diseases forever

5. If you "disagree" or "strongly disagree" to questions 1, 2, or 3 that providers should be able to perform PGD, which of the following statements best describes your reasons? (Please select all that apply)
    a. PGD leads to the unnecessary destruction of embryos
    b. PGD promotes discrimination against people with certain diseases
    c. PGD interferes with nature and places doctors in the role of "playing God"
    d. Widespread use of PGD may lead to unforeseen consequences
    e. There is no regulation of PGD

6. Providers should be able to perform PGD for sex selection.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

7. Providers should be able to perform PGD to screen for physical characteristics such as height, eye color or athleticism.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

8. Providers should be able to perform PGD to screen for personality traits such as intelligence or aggression.
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

9. Providers should be able to perform PGD to screen for sexual orientation such as homosexuality
    a. Strongly agree
    b. Agree
    c. Neither agree nor disagree
    d. Disagree
    e. Strongly disagree

10. If you “agree” or “strongly agree” to questions 6, 7, 8, or 9 that providers should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)

a. Couples should be able to make their own decisions about having a child
b. Selecting ideal traits will help a child lead a successful life
c. Selecting ideal traits will result in a better society

11. If you “disagree” or “strongly disagree” to questions 6, 7, 8, or 9 that providers should be able to use of PGD for selection of ideal traits, which of the following statements best describes your reasons? (Please select all that apply)

a. PGD leads to the unnecessary destruction of embryos
b. PGD promotes discrimination against people with certain characteristics
c. PGD interferes with nature and places doctors in the role of “playing God”
d. Widespread use of PGD may lead to unforeseen consequences
e. There is no regulation of PGD

Section 2

This section asks you for some basic background information. This information is for research reasons only. It will not be used to identify you in any way.

For the following question, please select the answer that best describes you

12. What Academy of Physician Assistants state are you a member of?

a. California
b. Kansas
c. Virginia

Thank you for taking the time to participate in our study.

# APPENDIX D

## Correspondences with CAPA, KAPA, VAPA

# Correspondences with CAPA, KAPA, VAPA

CAPA:

BETHEL UNIVERSITY

**Samantha Hamlin <samantha-j-hamlin@bethel.edu>**

## RE: Survey Request of Members

**Jonathan Kulesza** <jonathan@capanet.org> Wed, Feb 28, 2018 at 2:49 PM
To: "sah68693@bethel.edu" <sah68693@bethel.edu>
Cc: Maria Umphress <maria@capanet.org>, Gaye Breyman <gaye@capanet.org>

Good Afternoon Samantha,

Thank you for contacting the CAPA office. We have a dedicated section on our website where our members can select to participate in research surveys. Please click the link below to take a look at this page on our website.

http://capanet.org/research-surveys/

Once we receive the link to your research survey, along with a brief description of the survey, we will post it on our website. If you have any questions or require additional information, please let us know. Thank you and have a great day!

Sincerely,

**Jonathan Kulesza**

*Membership Services Representative*

CAPA
CALIFORNIA ACADEMY of PAS
*Empowering Healthcare*

2318 S. Fairview St

Santa Ana, CA 92704-4938

P: (714) 427-0321 . F: (714) 427-0324

Email: jonathan@capanet.org

Visit Us Online: www.capanet.org

**From:** Samantha Hamlin [mailto:sah68693@bethel.edu]
**Sent:** Wednesday, February 14, 2018 8:14 AM
**To:** Jonathan Kulesza
**Subject:** Survey Request of Members

To whom it may concern,

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are currently evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD). In order to compare perspectives from the East coast, Central US, and West Coast, we request permission to survey Physician Assistants from California. What are the next steps for obtaining approval to survey your members?

Thank you for your time.

Regards,
Samantha Hamlin

sah68693@bethel.edu

507-440-0561

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

## Survey Link for Academy Members

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Tue, Jul 10, 2018 at 11:54 AM
To: Jonathan Kulesza <jonathan@capanet.org>

Good Morning,

Thank you again for administering our survey project about Preimplantation Genetic Diagnosis to the members of your Academy.

Here is a short excerpt about the project:

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are conducting a research study to complete the Master's Thesis requirement for graduation. The research project will be evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD).

We have adapted a previously utilized survey for our use to analyze the PA members of Academies from the East Coast, Central US, and West Coast regions. The survey should take no more than 10 minutes to complete.

The survey can be found: https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD
Enter PassCode: PGD123

Thank you for taking the time to complete the survey!

Thank you for taking the time to facilitating and supporting our research.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

## Survey Link for Academy Members

4 messages

**Coryn Henderson** <coryn@capanet.org> Fri, Jul 13, 2018 at 1:52 PM
To: "samantha-j-hamlin@bethel.edu" <samantha-j-hamlin@bethel.edu>

Hi Samantha,

Jonathan sent me your email regarding your survey about Preimplantation Genetic Diagnosis. Can you send me a quick description that can be posted on the page with the survey link?

Thanks so much!

Sincerely,

**Coryn Henderson**

*Senior Administrative Generalist*

CAPA
CALIFORNIA ACADEMY of PAS
*Empowering Healthcare*

2318 S. Fairview St

Santa Ana, CA 92704-4938

P: (714) 427-0321 . F: (714) 427-0324

Visit Us Online: www.capanet.org

---

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Fri, Jul 13, 2018 at 2:02 PM
To: Coryn Henderson <coryn@capanet.org>

Hi,

I have included a short description below, if you would like more information, please let me know.

Thank you,

Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

This is the short description I sent in the previous email:

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are conducting a research study to complete the Master's Thesis requirement for graduation. The research project will be evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD).

We have adapted a previously utilized survey for our use to analyze the PA members of Academies from the East Coast, Central US, and West Coast regions. The survey should take no more than 10 minutes to complete.

The survey can be found: https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD
Enter PassCode: PGD123

Thank you for taking the time to complete the survey!

[Quoted text hidden]


**image001.png**
9K

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**Coryn Henderson** <coryn@capanet.org> Fri, Jul 13, 2018 at 2:13 PM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

Hi Samantha,

I think we are looking for more of a general description about the survey itself and something more in the 3rd person. Below is an example of a survey and description we have posted in the past:

> Philip T. Smith PA-C, MT (ASCP), Assistant Professor at the Mount St. Joseph University Physician Assistant program, is conducting research on the development and implementation of effective electronic health records systems and has requested PAs help in reaching a deeper understanding. Despite wide spread availability, very little research has been done to identify how and in what settings physician assistants are utilizing electronic tools to facilitate medical documentation. Mr. Smith has developed a survey that will quantify current adoption strategies and satisfaction with medical documentation across three specific patient settings - Inpatient, Outpatient, and Emergency Department. He will also collect additional information to determine the availability and usage of electronic shortcuts (canned text, defaults, etc) in the generation of electronic notes

specifically the history of present illness section. Results of this study will serve as the basis for a grant initiative to further refine and develop new technologies to facilitate easier more intuitive documentation platforms for all providers.

He is asking practicing Physician Assistants to complete this voluntary survey:

https://www.surveymonkey.com/

The survey instrument anonymous responses and will not track IP addresses. NO identifying data will be stored or maintained by completing the survey

Sincerely,

**Coryn Henderson**

*Senior Administrative Generalist*

CAPA
CALIFORNIA ACADEMY of PAs
*Empowering Healthcare*

2318 S. Fairview St

Santa Ana, CA 92704-4938

P: (714) 427-0321 . F: (714) 427-0324

Visit Us Online: www.capanet.org

**From:** Samantha Hamlin [mailto:samantha-j-hamlin@bethel.edu]
**Sent:** Friday, July 13, 2018 12:02 PM
**To:** Coryn Henderson
**Subject:** Re: Survey Link for Academy Members

[Quoted text hidden]

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**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Fri, Jul 13, 2018 at 5:00 PM
To: Coryn Henderson <coryn@capanet.org>

Hi,
I wrote a new description according to your request and the example provided. Please let me know if more changes need to be made.
Thank you,
Samantha Hamlin
sah68693@bethel.edu
507-440-0561

This is the description:
Sarah Barnes PA-S, Samantha Hamlin PA-S, and Claire Johnson PA-S, are Physician Assistant Students at Bethel University Physician Assistant program. They are conducting research on physician assistant approval and disapproval of the use of Preimplantation Genetic Diagnosis (PGD) and the approval and disapproval of PGD for specific conditions. Numerous studies have been conducted analyzing the general public's and physicians' understandings and approval/disapproval of PGD, but there are currently no studies researching physician assistant's approval or disapproval of PGD. This study aims to fill that void. Ms. Barnes, Ms. Hamlin, and Ms. Johnson have adapted a survey used previously to research the general public's rating of the use of PGD. The survey will quantify raw percentages of physician assistants' approval and disapproval of the use of PGD. Results of this study will further the research of the understandings and approval and/or disapproval of PGD overall and the use of PGD for specific conditions from physician assistants.

The research team is asking CAPA members to complete this voluntary survey:
https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD

Enter PassCode: PGD123

The responses are anonymous. No identifying information will be stored. Participation is voluntary.
[Quoted text hidden]

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Reminder Email of Survey Link for Academy Members

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Tue, Jul 31, 2018 at 1:59 PM
To: Coryn Henderson <coryn@capanet.org>

Good afternoon,

Thank you for your continued participation in our research project, regarding Physician Assistant views on PGD! As per our research design, we would like a reminder notification sent to members of your respective academy to encourage survey participation.

Here is the overview of our project:

Sarah Barnes PA-S, Samantha Hamlin PA-S, and Claire Johnson PA-S, are Physician Assistant Students at Bethel University Physician Assistant program. They are conducting research on physician assistant approval and disapproval of the use of Preimplantation Genetic Diagnosis (PGD) and the approval and disapproval of PGD for specific conditions. Numerous studies have been conducted analyzing the general public's and physicians' understandings and approval/disapproval of PGD, but there are currently no studies researching physician assistant's approval or disapproval of PGD. This study aims to fill that void. Ms. Barnes, Ms. Hamlin, and Ms. Johnson have adapted a survey used previously to research the general public's rating of the use of PGD. The survey will quantify raw percentages of physician assistants' approval and disapproval of the use of PGD. Results of this study will further the research of the understandings and approval and/or disapproval of PGD overall and the use of PGD for specific conditions from physician assistants.

The research team is asking CAPA members to complete this voluntary survey:
https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD

Enter PassCode: PGD123

The responses are anonymous. No identifying information will be stored. Participation is voluntary.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Reminder Email of Survey Link for Academy Members

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Wed, Aug 22, 2018 at 7:07 AM
To: Coryn Henderson <coryn@capanet.org>

Good afternoon,

Thank you for your continued participation in our research project, regarding Physician Assistant views on PGD! As per our research design, we would like a reminder notification sent to members of your respective academy to encourage survey participation.

Here is the overview of our project:

Sarah Barnes PA-S, Samantha Hamlin PA-S, and Claire Johnson PA-S, are Physician Assistant Students at Bethel University Physician Assistant program. They are conducting research on physician assistant approval and disapproval of the use of Preimplantation Genetic Diagnosis (PGD) and the approval and disapproval of PGD for specific conditions. Numerous studies have been conducted analyzing the general public's and physicians' understandings and approval/disapproval of PGD, but there are currently no studies researching physician assistant's approval or disapproval of PGD. This study aims to fill that void. Ms. Barnes, Ms. Hamlin, and Ms. Johnson have adapted a survey used previously to research the general public's rating of the use of PGD. The survey will quantify raw percentages of physician assistants' approval and disapproval of the use of PGD. Results of this study will further the research of the understandings and approval and/or disapproval of PGD overall and the use of PGD for specific conditions from physician assistants.

The research team is asking CAPA members to complete this voluntary survey:
https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD

Enter PassCode: PGD123

The responses are anonymous. No identifying information will be stored. Participation is voluntary.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Thank you for distribution of our survey

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Wed, Sep 5, 2018 at 7:37 PM
To: Coryn Henderson <coryn@capanet.org>

Good Evening,

This is Samantha Hamlin PA-S from Bethel University Physician Assistant Program, and you assisted in distribution of my research group's survey. The data collection of our survey has concluded. I would like to thank you for assisting in distribution of the survey of our research project which analyzed Physician Assistant agreement/disagreement of the use of Preimplantation Genetic Diagnosis (PGD).

We greatly appreciate you taking the time to distribute the survey and assisting in our data collection.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561



KAPA:

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

## Survey Request of Members

5 messages

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Fri, May 4, 2018 at 12:02 PM
To: kansaspa@sbcglobal.net

To whom it may concern,

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are currently evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD). In order to compare perspectives from the East coast, Central US, and West Coast, we request permission to survey Physician Assistants from Kansas. What are the next steps for obtaining approval to survey your members?

Thank you for your time.

Regards,
Samantha Hamlin
samantha-j-hamlin@bethel.edu
507-440-0561

**Douglas Smith** <kansaspa@sbcglobal.net> Fri, May 4, 2018 at 2:43 PM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

If you wish to provide a link to your survey we can distribute it along with explainer on the survey to our membership.

Thanks.

Doug Smith

Executive Director

Kansas Academy of Physician Assistants

Kansaspa@sbcglobal.net

**From:** Samantha Hamlin <samantha-j-hamlin@bethel.edu>
**Date:** Friday, May 4, 2018 at 12:02 PM
**To:** <kansaspa@sbcglobal.net>
**Subject:** Survey Request of Members

[Quoted text hidden]

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**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Mon, May 7, 2018 at 9:49 AM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good morning,

Thank you for the quick response. We are currently awaiting IRB approval. After approval, the link to the survey and a brief overview of the survey and project will be sent via email.

Thank you,
Samantha Hamlin
samantha-j-hamlin@bethel.edu
507-440-0561
[Quoted text hidden]

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**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Mon, May 7, 2018 at 9:57 AM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good Morning,

I apologize for another email, but I was wondering if you could provide me with the current percentage of PAs that are members of KAPA in reference to PAs practicing in the state?

Thank you,
Samantha Hamlin
samantha-j-hamlin@bethel.edu
507-440-0561
[Quoted text hidden]

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**Douglas Smith** <kansaspa@sbcglobal.net> Mon, May 7, 2018 at 11:35 AM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

Samantha,

We have 1,120 practicing PAs in KS and about 147 (13%) are members.

Doug

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**From:** Samantha Hamlin <samantha-j-hamlin@bethel.edu>
**Date:** Monday, May 7, 2018 at 9:57 AM
**To:** Douglas Smith <kansaspa@sbcglobal.net>
**Subject:** Re: Survey Request of Members

[Quoted text hidden]

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

## Survey Link for Academy Members

2 messages

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Tue, Jul 10, 2018 at 11:54 AM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good Morning,

Thank you again for administering our survey project about Preimplantation Genetic Diagnosis to the members of your Academy.

Here is a short excerpt about the project:

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are conducting a research study to complete the Master's Thesis requirement for graduation. The research project will be evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD).

We have adapted a previously utilized survey for our use to analyze the PA members of Academies from the East Coast, Central US, and West Coast regions. The survey should take no more than 10 minutes to complete.

The survey can be found: https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD
Enter PassCode: PGD123

Thank you for taking the time to complete the survey!

Thank you for taking the time to facilitating and supporting our research.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

---

**Douglas Smith** <kansaspa@sbcglobal.net> Tue, Jul 10, 2018 at 2:40 PM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

Samantha,

I sent a message out to our members with a link to your survey.

Good Luck!

Doug Smith

Executive Director

Kansas Academy of Physician Assistants

Kansaspa@sbcglobal.net

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**From:** Samantha Hamlin <samantha-j-hamlin@bethel.edu>
**Date:** Tuesday, July 10, 2018 at 11:54 AM
**To:** Douglas Smith <kansaspa@sbcglobal.net>
**Subject:** Survey Link for Academy Members

[Quoted text hidden]

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Reminder Email of Survey Link for Academy Members

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Tue, Jul 31, 2018 at 1:58 PM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good afternoon,

Thank you for your continued participation in our research project, regarding Physician Assistant views on PGD! As per our research design, we would like a reminder notification sent to members of your respective academy to encourage survey participation.

Here is the overview of our project:

Sarah Barnes PA-S, Samantha Hamlin PA-S, and Claire Johnson PA-S, are Physician Assistant Students at Bethel University Physician Assistant program. They are conducting research on physician assistant approval and disapproval of the use of Preimplantation Genetic Diagnosis (PGD) and the approval and disapproval of PGD for specific conditions. Numerous studies have been conducted analyzing the general public's and physicians' understandings and approval/disapproval of PGD, but there are currently no studies researching physician assistant's approval or disapproval of PGD. This study aims to fill that void. Ms. Barnes, Ms. Hamlin, and Ms. Johnson have adapted a survey used previously to research the general public's rating of the use of PGD. The survey will quantify raw percentages of physician assistants' approval and disapproval of the use of PGD. Results of this study will further the research of the understandings and approval and/or disapproval of PGD overall and the use of PGD for specific conditions from physician assistants.

The research team is asking CAPA members to complete this voluntary survey:
https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD

Enter PassCode: PGD123

The responses are anonymous. No identifying information will be stored. Participation is voluntary.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

BETHEL UNIVERSITY

Samantha Caron <samantha-j-caron@bethel.edu>

## Reminder Email of Survey Link for Academy Members

1 message

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Wed, Aug 22, 2018 at 7:08 AM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good morning,

Thank you for your continued participation in our research project, regarding Physician Assistant views on PGD! As per our research design, we would like a reminder notification sent to members of your respective academy to encourage survey participation.

Here is the overview of our project:

Sarah Barnes PA-S, Samantha Hamlin PA-S, and Claire Johnson PA-S, are Physician Assistant Students at Bethel University Physician Assistant program. They are conducting research on physician assistant approval and disapproval of the use of Preimplantation Genetic Diagnosis (PGD) and the approval and disapproval of PGD for specific conditions. Numerous studies have been conducted analyzing the general public's and physicians' understandings and approval/disapproval of PGD, but there are currently no studies researching physician assistant's approval or disapproval of PGD. This study aims to fill that void. Ms. Barnes, Ms. Hamlin, and Ms. Johnson have adapted a survey used previously to research the general public's rating of the use of PGD. The survey will quantify raw percentages of physician assistants' approval and disapproval of the use of PGD. Results of this study will further the research of the understandings and approval and/or disapproval of PGD overall and the use of PGD for specific conditions from physician assistants.

The research team is asking CAPA members to complete this voluntary survey:
https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD

Enter PassCode: PGD123

The responses are anonymous. No identifying information will be stored. Participation is voluntary.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Thank you for distributing our survey

2 messages

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Wed, Sep 5, 2018 at 7:37 PM
To: Douglas Smith <kansaspa@sbcglobal.net>

Good Evening,

This is Samantha Hamlin PA-S from Bethel University Physician Assistant Program, and you assisted in distribution of my research group's survey. The data collection of our survey has concluded. I would like to thank you for assisting in distribution of the survey of our research project which analyzed Physician Assistant agreement/disagreement of the use of Preimplantation Genetic Diagnosis (PGD).

We greatly appreciate you taking the time to distribute the survey and assisting in our data collection.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

**Douglas Smith** <kansaspa@sbcglobal.net> Thu, Sep 6, 2018 at 9:49 AM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

Certainly.

Good luck.

Doug

**From:** Samantha Hamlin <samantha-j-hamlin@bethel.edu>
**Date:** Wednesday, September 5, 2018 at 7:37 PM
**To:** Douglas Smith <kansaspa@sbcglobal.net>
**Subject:** Thank you for distributing our survey

[Quoted text hidden]



VAPA:

BETHEL UNIVERSITY

**Samantha Hamlin <samantha-j-hamlin@bethel.edu>**

## Survey Request of Members

**Devon Possanza** <Devon.Possanza@easterassociates.com> Thu, Feb 15, 2018 at 9:55 AM
To: Samantha Hamlin <sah68693@bethel.edu>

Hi Samantha, if you have a link to your survey, we're happy to post it on our Facebook page.

Devon Possanza

Deputy Executive Director

**Virginia Academy of Physician Assistants**

1011 East Main Street, Suite 227

Richmond, VA 23219

Main: 804-643-4433

Email: devon.possanza@easterassociates.com

**From:** Samantha Hamlin [mailto:sah68693@bethel.edu]
**Sent:** Wednesday, February 14, 2018 11:16 AM
**To:** vapa@vapa.org
**Subject:** Survey Request of Members

[Quoted text hidden]

BETHEL UNIVERSITY

**Samantha Caron <samantha-j-caron@bethel.edu>**

## Survey Link for Academy Members

2 messages

**Samantha Hamlin** <samantha-j-hamlin@bethel.edu> Tue, Jul 10, 2018 at 11:54 AM
To: Devon Possanza <Devon.Possanza@easterassociates.com>

Good Morning,

Thank you again for administering our survey project about Preimplantation Genetic Diagnosis to the members of your Academy.

Here is a short excerpt about the project:

My name is Samantha Hamlin PA-S at Bethel University in Arden Hills, MN, and I am conducting a research study with two other graduate students, Sarah Barnes PA-S and Claire Johnson PA-S. We are conducting a research study to complete the Master's Thesis requirement for graduation. The research project will be evaluating Physician Assistants' perspectives, understandings, and ethical considerations in regard to Preimplantation Genetic Diagnosis (PGD).

We have adapted a previously utilized survey for our use to analyze the PA members of Academies from the East Coast, Central US, and West Coast regions. The survey should take no more than 10 minutes to complete.

The survey can be found: https://bethel.qualtrics.com/jfe/form/SV_0epwwWQCvWH1ipD
Enter PassCode: PGD123

Thank you for taking the time to complete the survey!

Thank you for taking the time to facilitating and supporting our research.

Thank you,
Samantha Hamlin PA-S
sah68693@bethel.edu
507-440-0561

**Devon Possanza** <Devon.Possanza@easterassociates.com> Mon, Jul 16, 2018 at 1:01 PM
To: Samantha Hamlin <samantha-j-hamlin@bethel.edu>

Hi Samantha,

The VAPA Board of Directors has recently discussed the policy on sending student surveys to our membership. As there are 8 PA programs in Virginia, we no longer post surveys from out of state. I apologize for any inconvenience; please let me know if you have any questions.

Devon Possanza

Deputy Executive Director

**Virginia Academy of Physician Assistants**

1011 East Main Street, Suite 227

Richmond, VA 23219

Main: 804-643-4433

Email: devon.possanza@easterassociates.com

**From:** Samantha Hamlin <samantha-j-hamlin@bethel.edu>
**Sent:** Tuesday, July 10, 2018 12:55 PM
**To:** Devon Possanza <Devon.Possanza@easterassociates.com>
**Subject:** Survey Link for Academy Members

[Quoted text hidden]

# APPENDIX E

## Informed Consent, Statement of Confidentiality, and Study's Purpose

Informed Consent, Statement of Confidentiality, and Study's Purpose:

You are invited to participate in a study that is being conducted by Minnesota Physician Assistant Students from Bethel University's Physician Assistant Program, which is a partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. The purpose of the study is to analyze the understandings, perspectives, and ethical considerations physician assistants hold in relation to preimplantation genetic diagnosis (PGD). You were selected as a possible participant in this study because you are a physician assistant practicing in California, Kansas, or Virginia.

Participation in the study is voluntary. If you decide to participate, participation involves a short, 10-minute online survey adapted by researchers from Bethel University's PA Program. The survey questions will ask about your understanding, utilization, and ethical implications of PGD. If you feel uncomfortable in any way during the online survey, you have the right to skip the question or discontinue the survey with no penalty.

No identifying information will be collected, and data will be stored on an encrypted flashdrive and locked in a Bethel University Graduate Studies staff's office. In any written reports or publications, only aggregate data will be presented, in order to maintain anonymity. Your decision whether or not to participate will not affect your future relations with Bethel University, CAPA, KAPA, or VAPA in any way.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research related injury, please call the contacts listed below. If you so choose, a copy of this informed consent can be offered to you to keep.

We understand that you have an extremely busy schedule and your time is limited. The information that you provide is essential to the validity of this study. Thank you in advance for your participation in this study. If you have any questions, please contact Research Chair: Christina Hanson PA-C, 651-635-8042, Research Committee Member: Jeanne Szarzynski, 651-635-8002, Researcher: Sarah Barnes, 952-843-8696, Researcher: Samantha Hamlin, 507-440-0551, Researcher: Claire Johnson, 612-280-1282.

By continuing with the survey, you have read the information that is provided above, and you are granting consent to participate in this research. Thank you again for your help.