**Forum:** World Health Organization (WHO)
**Issue:** Examining the use of polygenic screening in In-Vitro-Fertilization (IVF) for genetic mental health issues
**Student Officer:** Nefeli Papadiamantopoulou
**Position:** Deputy President

## Personal Introduction

Dear delegates,

My name is Nefeli Papadiamantopoulou and I am currently an AS-Level student at Byron College. I commenced my MUN journey approximately 2.5 years ago, experimenting with different committees and positions. MUN has truly aided me in bettering my perspective of crucial current issues and enhanced my debating skills while allowing me to meet and connect with people of different cultural backgrounds, which I assume is the case for you too. This year's ACG MUN will be my 8th time attending and it is my utmost honor to have you as my first committee where I'll be assisting you as a Deputy President.

This year's topic 3 of the World Health Organisation committee, based on the theme of balancing infinite opportunities, is "Examining the use of polygenic screening in In-Vitro-Fertilization (IVF) for genetic mental health issues". This specific topic is a very intricate and multifaceted issue, especially in the 21st century. Following the rapid advancement of technology in the medical field it is vital that we consider the ethical and technical setbacks that the rise of new techniques are accompanied by. I hope you find this topic as interesting as I do and I look forward to meeting you all and the fruitful debate to come!

If you have any questions please do not hesitate to contact me via email at: n.papadiamantopoulou@pupils.byroncollege.gr

Best Regards,
Nefeli Papadiamantopoulou

## Topic Introduction

Over the past 3 years, especially following the COVID-19 pandemic, there has been a significant augmentation in mental health disorders globally amplifying the fear of mental health disorders developing in children. According to the World Health Organization (WHO), during the first year of the pandemic, the frequency of anxiety and depression increased by a staggering 25%[1]. Moreover, the NIH's (National Institute of Health)[2] Research suggests that individuals have a higher probability of presenting mental health issues in the months following a COVID-19 infection and people who endured a COVID-19 infection for a long period of time are more likely to exhibit symptoms correlated to mental health and brain function. Consequently, due to the increase in technological device usage during the lockdown, which continued as a result of acquired habit, the alteration in mental health issues observed continued. The NIH reports that over 25% of adults from a recent study showcased high-severe smartphone use and the rest still had some dependency as well although more moderate.

As a result, parents have become more and more determined to do everything in their power in an attempt to prevent their children from inheriting mental health genes that would make them more likely to express the condition later on in life. This is where the concept of IVF and PGT are involved, where a parent who may be experiencing infertility difficulties may be able to overcome those previously perceived as insurmountable obstacles with the aid of IVF. PGT was first introduced in 1990 when it was utilized on sex embryos by Handyside and ever since it has been globally performed to diminish the possibilities of genetic traits such as hereditary diseases being expressed by offspring. [3]

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[1] "Covid-19 Pandemic Triggers 25% Increase in Prevalence of Anxiety and Depression Worldwide." *World Health Organization*, World Health Organization, www.who.int/news/item/02-03-2022-covid-19-pandemic-triggers-25-increase-in-prevalence-of-anxiety-and-depression-worldwide Accessed 11 Jan. 2025.

[2] National Institute of Mental Health. "COVID-19 and Mental Health - National Institute of Mental Health (NIMH)." Www.nimh.nih.gov, May 2024, www.nimh.nih.gov/health/topics/covid-19-and-mental-health
Pfcla. "History of IVF: Origin and Developments of the 20th Century." *PFCLA*, PFC Management LLC, 27 July 2022, www.pfcla.com/blog/history-of-ivf

[3] Takeuchi, Kazuhiro. "Pre-Implantation Genetic Testing: Past, Present, Future." *Reproductive Medicine and Biology*, U.S. National Library of Medicine, 13 Oct. 2020, pmc.ncbi.nlm.nih.gov/articles/PMC7812490/#:~:text=Pre%E2%80%90implantation%20genetic%20testing%20(PGT,to%20sex%20embryos%20in%201990

Although the use of PGT has proven to be extremely beneficial in some cases we must not forget that genetic modification is always accompanied by significant considerations that need to be taken into account. For example, the mitigation of all genetic mental health disorders from a large quantity of embryos may result in stigma formulating around the groups of people who have to endure them daily(people with mental health disorders) who are considered a minority. Due to the prosecution they have faced for decades this practice may be viewed as a way of enhancing the stigma surrounding mental health in general and making it more challenging for individuals struggling to reach out for help. Moreover, stigma could simultaneously develop around the offspring of which genes were modified with PGT's assistance. PGT is also widely viewed as a process that interferes with natural occurrences and many believe that it strips the embryos that aren't specifically selected of their right to life. Therefore, to link back to this year's theme of balancing limitless opportunities, when discussing the use of IVF and PGT in the medical field we must highlight the contrast between the ethical considerations and limitless opportunities that are available for the embryo's genes to create a balance. Each individual embryo had the potential to develop into an independent and unique human being but the use of PES and PGT might have prevented it from materializing.

## Definition of Key Terms

### Genetics

"The study of genes and heredity. Heredity is the passing of genetic information and traits (such as eye color and an increased chance of getting a certain disease) from parents to offspring."[4]

### Eugenics

[4] "National Cancer Institute." *www.cancer.gov*, 2 Feb. 2011, www.cancer.gov/publications/dictionaries/cancer-terms/def/genetics

"The selection of desired heritable characteristics in order to improve future generations, typically in reference to humans."[5]

**In-Vitro-Fertilization (IVF)**

"A procedure in which eggs are removed from a woman's ovary and combined with sperm outside the body to form embryos. The embryos are grown in the laboratory for several days and then either placed in a woman's uterus or cryopreserved (frozen) for future use."[6]

**Preimplantation Genetic Testing (PGT)**

"Preimplantation genetic testing (PGT) is a cutting-edge procedure used to identify genetic abnormalities in embryos created with in vitro fertilization (IVF)."[7]

**PGT-P**

PGT-P is the preimplantation testing for polygenic disorders which assesses the polygenic risk .

**Polygenic Embryo Screening (PES)**

"Polygenic embryo screening (PES) is a new technique in which each embryo derived from a cycle of IVF is densely genotyped, using DNA microarrays or sequencing, and the data are used to generate polygenic risk scores (PRSs) to estimate the risk of a disease or the potential phenotypic value of a quantitative trait for each embryo."[8]

**Polygenic Risk Scores (PRS)**

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[5] Wilson, Philip K. "Eugenics." *Encyclopædia Britannica*, 20 Dec. 2018, www.britannica.com/science/eugenics-genetics

[6] National Cancer Institute. "Https://Www.cancer.gov/Publications/Dictionaries/Cancer-Terms/Def/In-Vitro-Fertilization." Www.cancer.gov, 2 Feb. 2011, www.cancer.gov/publications/dictionaries/cancer-terms/def/in-vitro-fertilization

[7] "Preimplantation Genetic Testing (PGT)." *Fertility Reproductive Medicine Center*, fertility.wustl.edu/treatments-services/genetic-counseling/preimplantation-genetic-testing-pgt/#:~:text=Preimplantation%20genetic%20testing%20(PGT)%20is,or%20chromosome%20abnormalities%20for%20transfer Accessed 19 Jan. 2025.

[8] Lencz, Todd, et al. "Concerns about the Use of Polygenic Embryo Screening for Psychiatric and Cognitive Traits." The Lancet Psychiatry, vol. 9, no. 10, 1 Oct. 2022, pp. 838–844, www.sciencedirect.com/science/article/abs/pii/S2215036622001572, https://doi.org/10.1016/S2215-0366(22)00157-2

"An assessment of the risk of a specific condition based on the collective influence of many genetic variants. These can include variants associated with genes of known function and variants not known to be associated with genes relevant to the condition."[9]

**Genome-Wide Association Studies (GWAS)**

"A genome-wide association study (abbreviated GWAS) is a research approach used to identify genomic variants that are statistically associated with a risk for a disease or a particular trait. The method involves surveying the genomes of many people, looking for genomic variants that occur more frequently in those with a specific disease or trait compared to those without the disease or trait."[10]

**Monogenic Conditions**

"Monogenic diseases are those in which the disease state in a family is determined by a single mutation"[11]

**Polygenic Conditions**

"A condition or trait resulting from the combined action of more than one gene."[12]

**Single Nucleotide Polymorphisms (SNPs)**

[9] "Https://Www.cancer.gov/Publications/Dictionaries/Genetics-Dictionary/Def/Polygenic-Risk-Score." Www.cancer.gov, 20 July 2012, www.cancer.gov/publications/dictionaries/genetics-dictionary/def/polygenic-risk-score

[10] Hutter, Carolyn. "Genome-Wide Association Studies (GWAS)." Genome.gov, 2024, www.genome.gov/genetics-glossary/Genome-Wide-Association-Studies-GWAS

[11] "Monogenic Disorder - an Overview | ScienceDirect Topics." *Www.sciencedirect.com*, www.sciencedirect.com/topics/medicine-and-dentistry/monogenic-disorder

[12] "Polygenic Condition." Genomics Education Programme, www.genomicseducation.hee.nhs.uk/glossary/polygenic-condition/

"A single nucleotide polymorphism, or SNP is a variation at a single position in a DNA sequence among individuals."[13]

**Assisted reproductive technology (ART)**

"All fertility treatments or procedures in which either eggs or embryos are handled to help achieve a pregnancy."[14]

## Background Information

### Historical Background on In-Vitro-Fertilization

The notion of IVF to overcome the infertility of some women when naturally conceiving a child began in the early 1950s at the Worcester Foundation where Dr. Min Chueh Chang innovated this new technique and successfully delivered baby rabbits engraving his name in history. This was the first concrete evidence that an embryo that had been fertilized in what was perceived as an 'unnatural' way, in a lab could be successfully transferred and grown in the womb. In the following two decades, many failed attempts followed in trying to adapt this process for human embryos until finally in 1978 the very first human IVF pregnancy and live birth was achieved by Dr. Robert Edwards and Dr. Patrick Steptoe in England[15]. The child born was Louise Brown and she marked a new beginning of the revolution of infertility treatments as her existence put IVF under the limelight and led to it being widely accessible shortly after in the 1980s. Nowadays, thousands of women are provided with the opportunity to become mothers because of IVF either by carrying the fertilized embryo themselves or by using surrogacy instead.

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[13] Scitable. "Single Nucleotide Polymorphism / SNP | Learn Science at Scitable." Nature.com, 2014, www.nature.com/scitable/definition/snp-295/

[14] "About Art." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, 10 Dec. 2024, www.cdc.gov/art/about/index.html#:~:text=Assisted%20reproductive%20technology%20(ART)%20includes,the%20definition%20of%20ART%20below

[15] Pfcla. "History of IVF: Origin and Developments of the 20th Century." *PFCLA*, PFC Management LLC, 27 July 2022, www.pfcla.com/blog/history-of-ivf

### Advantages of the use of IVF

Beyond the obvious value of IVF in aiding women or men with infertility issues to produce offspring, the advantages of IVF range in all aspects. An undeniable fact is that IVF increases the success rate of a full-term pregnancy, sometimes ranging from extremely small figures to up to 55%.[16] Furthermore, it allows for individuals to be in control of the specific time at which their pregnancy will commence and be able to schedule it for convenience. Upon the notion of PES, for some, it is considered a great privilege to select healthier embryos to implant as genetic diseases that they carry often influence their decision to become parents and risk passing it on to their future children. Thus, PES in IVF provides them with an alternate pathway in which they don't have to worry about genetic health conditions that may later develop in their embryo such as breast cancer.

### Issues and Disadvantages Surrounding IVF

Even though there is a plethora of positive effects accompanying IVF we must disregard its possible negative outcomes. Firstly, although the success rate can be significantly increased it is not guaranteed, meaning that even after multiple cycles of IVF a woman may still be unable to grow an embryo. Consequently, there might be detrimental effects on her mental health, including anxiety and depression. Moreover, if a woman is able to commence the first trimester of her pregnancy the risk of miscarriage is nevertheless present as well as the risk of premature delivery which is further increased.

## Preimplantation Genetic Testing (PGT) and Polygenic Embryo Screening (PES)

After the introduction of IVF into the medical field and its rapid success scientists took this opportunity to develop a way in which its possible to distinguish embryos that are healthy from embryos that carry hereditary genetic conditions such as diabetes and

[16] Pfcla. "IVF Success Rates & Statistics." *PFCLA IVF Clinic Blog*, Hatch Fertility, 10 Jan. 2025, www.pfcla.com/blog/ivf-success-rates-statistics#:~:text=IVF%20technology%20has%20made%20significant,the%20technology%20was%20first%20introduced

cancer, known as PGT. PGT is carried out by performing a biopsy where 2-3 cells of the potential embryos are removed. Then an analysis of the biopsy occurs and the DNA of the cells is genetically tested for conditions.[17] PES is a form of PGT often called PGT-P which analyzes the genotype data of the embryo and produces Polygenic Risk Scores for certain diseases or traits. However, as the purpose of PES is to take into account multiple genes and their combinations that cause the disease, the Polygenic Risk Scores produced are merely an estimation of the likelihood of the condition later developing, do not determine if will undoubtedly develop, and are solely a measure of one of many possible risk factors.

**Advantages of PGT and PES**

The benefits of PGT and PES in specific circumstances can be major. For example, hey are currently the most advanced tool in preventing possibly fatal conditions such as cystic fibrosis and breast cancer.[18] Moreover, the selection of a healthier embryo may ameliorate an IVF pregnancy while increasing the possibility of a successful IVF cycle and also providing parents with the choice of sex. Furthermore, it's a source of emotional reassurance for parents as frequently the psychological toll of producing offspring with a high possibility of inheriting a hereditary disease is substantial. For the wider scientific community, PGT aids improvement in genetic makeup studies such as the human genome project, and genetics contributing hugely to the comprehension of genetics.

**Disadvantages of PGT and PES**

Beyond the clear advantages of genetic testing, the technique has given rise to multiple concerns for both mothers and the embryos. Considering its novelty in medicine, the accessibility to PGT is incredibly high with many Nordic countries

[17] Giuliano, Roberta, et al. "Preimplantation Genetic Testing for Genetic Diseases: Limits and Review of Current Literature." *Genes*, U.S. National Library of Medicine, 17 Nov. 2023, pmc.ncbi.nlm.nih.gov/articles/PMC10671162/

[18] Lencz, Todd, et al. "Concerns about the Use of Polygenic Embryo Screening for Psychiatric and Cognitive Traits." *The Lancet. Psychiatry*, U.S. National Library of Medicine, 2 Aug. 2022, https://pmc.ncbi.nlm.nih.gov/articles/PMC9930635/

offering it even in national clinics[19]. Due to the requirement of an embryo biopsy which is an invasive procedure, there is a possibility of damage to either the embryo or the mother. Moreover, as the process of PGT and especially PES isn't 100% accurate in producing results the testing might still produce false results, misleading consultants and parents into choosing the wrong embryos to implant and discarding healthy ones.[20] In the early 2000s, a couple underwent PGT through IVF to avoid passing on the gene carrying the cystic fibrosis mutation to their children. After the genetic testing, one of the embryos appeared to be free of the gene and was implanted. However, after the child was born it was proven that the disease was inherited and the PGT exhibited false results. Lastly, as PGT is an expensive procedure that requires the expertise of various professionals, the cost is often a major factor in preventing prospective parents from selecting it.

## Preimplantation Embryo Screening in Regards to Genetic Mental Health Issues

### Scientific Concerns

Genetic mental health conditions have been passed down from generation to generation throughout time and seeking a solution to that, scientists started experimenting with PGT to invent a way of detecting the risk of an embryo developing hereditary mental health conditions. However, the concept of PES is relatively new thus very little research has been conducted on the short and long-term effects of PES for detecting psychiatric disorders. The genetic component of mental health disorders is highly polygenic - meaning that they are not determined by a single gene, making it extremely difficult to detect thousands of specific variants that cause each disorder. Moreover, beyond the genetic aspect, they depend on various factors such as the environment in which the offspring are

[19] "Preimplantation Genetic Testing Legislation and Accessibility in the Nordic Countries - Hreinsson - 2020 - Acta Obstetricia et Gynecologica Scandinavica - Wiley Online Library." *Obgyn Online Library*, obgyn.onlinelibrary.wiley.com/doi/10.1111/aogs.13831 Accessed 19 Jan. 2025.

[20] Butler. "A Guide to Preimplantation Genetic Testing (PGT): Fertility Center." *A Guide to Preimplantation Genetic Testing (PGT) | Fertility Center*, fertility.womenandinfants.org/treatment/preimplantation-genetic-testing#:~:text=Another%20risk%20of%20PGT%20is,is%20pregnant%2C%20such%20as%20amniocentesis Accessed 19 Jan. 2025.

raised. Furthermore, according to the International Society of Psychiatric Genetics (ISPG) in May of 2021, the polygenic risk scores that are produced are not specific to a single condition and therefore selecting one condition may affect other genetic traits.[21]

**Ethical Concerns**

The PRS produced from PES are classified as non-specific, meaning that PRS affect one another. Consequently, choosing to eliminate a condition with a high PRS may increase the PRS of another one. For example, according to the National Institute of Health if an embryo exhibiting a low bipolar or schizophrenia PRS is selected it could lead to reduced creativity, and if an embryo showcasing higher educational attainment is selected it could increase the risk of bipolar disorder developing by 16%.[22] However, in a conflicting view, some ethicists argue that parents have a moral obligation to select children who are likely to have the best chance of having the best life possible.

[21] Lencz, Todd, et al. "Concerns about the Use of Polygenic Embryo Screening for Psychiatric and Cognitive Traits." The Lancet. Psychiatry, U.S. National Library of Medicine, 2 Aug. 2022, https://pmc.ncbi.nlm.nih.gov/articles/PMC9930635/

[22] Lencz, Todd, et al. "Concerns about the Use of Polygenic Embryo Screening for Psychiatric and Cognitive Traits." The Lancet. Psychiatry, U.S. National Library of Medicine, 2 Aug. 2022, https://pmc.ncbi.nlm.nih.gov/articles/PMC9930635/

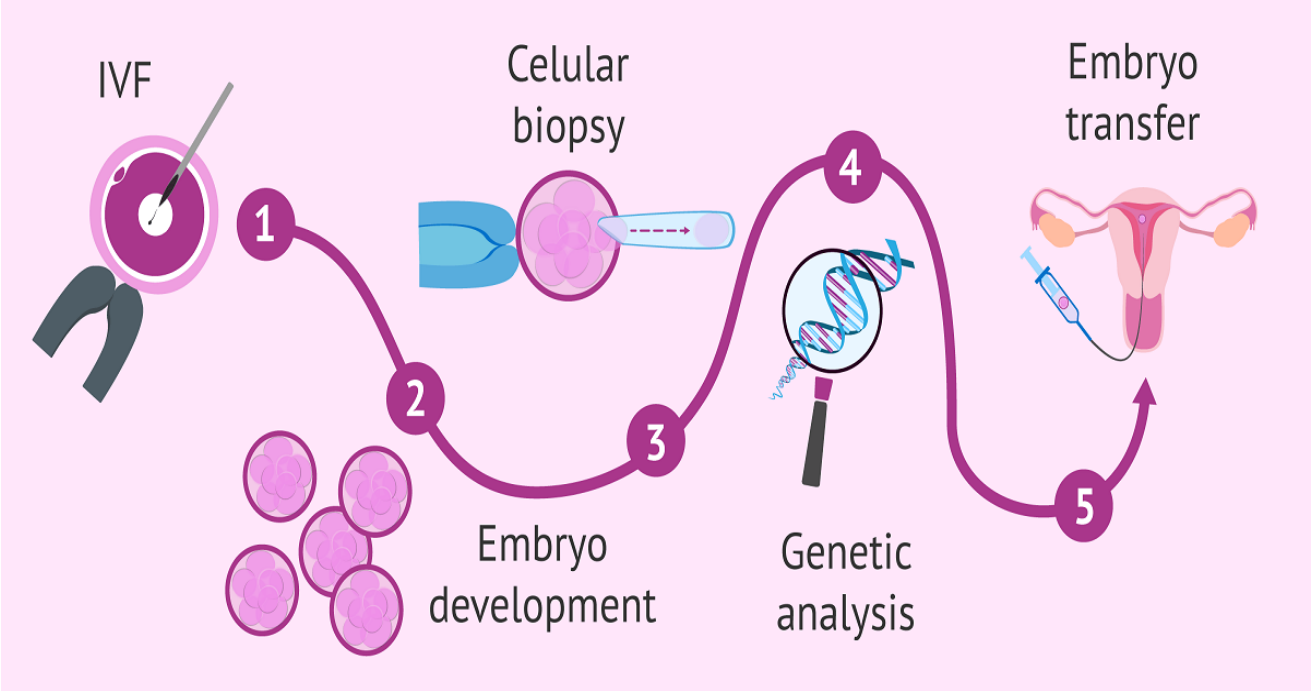


Figure 1: Image depicting the process of PGT during IVF [23]

## Major Countries and Organizations Involved

### United States of America (USA)

Ever since the invention of PGT, there has been rapid development and access to preimplantation genetic testing in the USA. As PES has only recently been integrated into US clinics there aren't any regulations yet specifically designed for it, but it does follow the legislation for PGT. The USA has been characterized by the Stanford School of Law as a nation with "one of the most permissive regulatory frameworks" for PGT as it has no federal or state statutes, regulations, or legislation and no state currently has laws regulating the use of PGT. [24] Moreover, the United States Food and Drug Administration (FDA) has not yet approved or validated the PGT test and doesn't provide oversight over

[23] Dr. Mona Dahiya. "What Is Preimplantation Genetic Testing & Diagnosis?" *Little Angel IVF*, Little Angel IVF, 30 July 2023, www.littleangelivf.com/blog/ivf/what-is-preimplantation-genetic-testing-diagnosis/
[24] School, Stanford Law. "PGT-A under the Spotlight." Stanford Law School, 10 Feb. 2023, https://law.stanford.edu/2023/02/10/pgt-a-under-the-spotlight/

it.[25] However, the Genomic Prediction in the USA offers polygenic testing for genetic mental health disorders.

**China**

China is one of the most advanced countries in terms of genomics and genetic makeup studies with fast-evolving research programs. It introduced its 'Precision Medicine Initiative' in 2016 aiming at promoting the use of precision medicine through innovative genomics, personalized treatments, and utilizing data-based healthcare. It currently has a government-funded database that includes samples from millions of pregnant women for the purpose of genetic research. Moreover, due to China's infamous one-child policy which lasted up until 2016, it was essential for parents to choose embryos with a higher chance of life and a better overall life as they had only one chance at it. However, China doesn't disregard the need for methods of regulation of PGT and the development of more accurate genetic testing. [26]

**United Kingdom (UK)**

On the other hand, the UK has significantly stricter regulations regarding the use of PGT and PES in IVF. The Human Fertilization and Embryology Authority (HFEA) has strictly overseen the usage of PGT and hasn't yet approved PES. Issues surrounding its use keep arising due to continuing ethical and scientific concerns and unease about its predictive accuracy and validity preventing the UK from allowing its overutilization. Overall, the UK has very demanding standards for the approval of PGT and PES and there is still ongoing debate about whether PES will get validated for clinics.

[25] School, Stanford Law. "PGT-A under the Spotlight." *Stanford Law School*, 10 Feb. 2023, https://law.stanford.edu/2023/02/10/pgt-a-under-the-spotlight/

[26] Liu Y;Ren Y;Feng H;Wang Y;Yan L;Qiao J;Liu P; "Development of Preimplantation Genetic Testing for Monogenic Diseases in China." *Human Fertility (Cambridge, England)*, U.S. National Library of Medicine, 17 Dec. 2023, pubmed.ncbi.nlm.nih.gov/38059330/

**India**

India is one of the few Lower Economically Developed Countries(LEDCs) that actively encourage and practice PGT however it is reluctant to allow PES to be widely practiced before there is more robust scientific evidence available. Because of the growing concern of the misuse of PGT in India, every clinic that practices it must be a registered ART clinic and follow the Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT) Act of 1994 which prevents the unethical misuse of PGT especially concerning its use for sex-selective purposes which is a common issue in the Eastern states.[27]

**Germany**

Germany's approach to PGT and PES follows a more restrictive framework, guided by its Embryo Protection Act (1990). PGT is only allowed under specific circumstances where there is a high risk of miscarriage or of inheriting serious genetic diseases when the parents have known genetic issues. Moreover, before the procedure approval needs to be earned by an ethics committee to ensure that its use is solely for medical reasons and not for enhancement purposes. Similarly, as Germany's legal framework strictly opposes genetic selection PES is approached with the same cautiousness.

**European Union (EU)**

Throughout the EU the stances on PGT and PES vary hugely. PGT is generally permitted in most European countries for the prevention of chromosomal abnormalities or severe genetic conditions. Some countries, however, experience a divide with their approaches as some prefer permissive regulations (i.e. Netherlands, Belgium, Spain) and others have adopted more restrictive regulations (i.e. Germany, Italy) which follow the Embryo Protection Act of 1990. However, in regards to PES, there appears to be a consensus between the EU countries as it isn't widely regulated or practiced due to

[27] "Pre-Conception & Pre-Natal Diagnostic Techniques Act, 1994." *India Code*, 20 Sept. 1994, www.indiacode.nic.in/bitstream/123456789/8399/1/pre-conception-pre-natal-diagnostic-techniques-act-1994.pdf

significant ethical and scientific concerns such as its non-specificity, reliability, and accuracy in detecting more complex conditions.

**United Nations (UN)**

The UN includes key bodies such as UNESCO and WHO that strive to promote the proper use of PGT and PES. According to WHO's Human Genome Editing Recommendations (2021), it suggests that Assisted Reproductive Technology (ART) should only be used in ways that are safe, ethical, and equitable. However, this document provides mere recommendations and the WHO doesn't have significant regulatory power over the nations of the UN. Moreover, UNESCO endeavors to set international standards for PGT while highlighting the importance of bioethics, social concerns, and human rights in that field. The International Bioethics Committee (IBC), which advises UNESCO on matters related to genetics and biomedicine has expressed that they should be approached with caution and that there's a need for ethical oversight, transparency, and global dialogue.[28]

**Center for Reproductive Rights (CRR)**

The Center for Reproductive Rights is the only global legal advocacy organization dedicated to advancing reproductive rights and aims at fostering reproductive autonomy and preventing serious genetic disorders through the responsible use of PGT. However, due to PES's potential to raise issues encompassing discrimination, genetic enhancement, and equity concerns, it is approached with more hesitation. Overall, the CRR stance emphasizes the need for informed consent, prevention against discrimination, equitable access, and adherence to the ethical usage of PGT.

## Blocs Expected

**Alliance 1:** The first alliance consists of countries that are more accepting of PGT and PES practices, encourage technological advancement for altering genetics and are likely

[28] "Un Panel Warns against 'Designer Babies' and Eugenics in 'Editing' of Human DNA | UN News." *United Nations*, United Nations, 5 Oct. 2015, news.un.org/en/story/2015/10/511732#:~:text=But%20the%20IBC%20added%3A%20%E2%80%9CInterventions,renew%20eugenics%2C%E2%80%9D%20it%20said

to allow PES to occur for mental health purposes given that there are regulations in place e.g. United States, Singapore, China,

**Alliance 2:** The second alliance formed will most likely consist of countries that are more reluctant to allow PES for mental health practices and generally have stricter regulations in place for PGT and PES  e.g.United Kingdom, Germany, France

## Timeline of Events

| Date | Description of Event |
|---|---|
| February 27th 1975 | Asilomar Conference on Gene Editing discussed the social, ethical, and legal implications of DNA and RNA editing technologies |
| October 24th 1990 | Embryo Protection Act by Germany aimed at creating strict legal framework for reproductive technologies |
| September 20th 1994 | Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT) Act aimed at preventing the unethical misuse of PGT |
| November 11th 1997 | UNESCO's Universal Declaration on the Human Genome and Human Rights accentuated the importance of maintaining human dignity and human rights regarding genetic testing and research |
| March 10th 1999 | UN General Assembly Resolution on the Human Genome and Human Rights aimed at promoting the ethical use of technologies regarding genetics while ensuring the protection of human rights |
| September 21st 2001 | Global Consultation on Assisted Reproductive Technologies intended to address ethical, social, and legal issues emerging from ART |

| | |
|---|---|
| 2007 | Development of first polygenic risk scores (PRS) with the utilization of GWAS data |
| July 20th 2021 | Human Genome Editing Recommendations by WHO providing recommendations to the global scientific community for the use of human genome editing, highlighting that its use should be for public health purposes |

## Relevant UN Resolutions, Treaties & Events

- Universal Declaration on the Human Genome and Human Rights, 11 November 1997
- Global Consultation on Assisted Reproductive Technologies, 2001
- UN General Assembly Resolution on Genetics and Human Rights (A/RES/53/152) 1999

## Previous Attempts to Solve the Issue

### Asilomar Conferences on Gene Editing

The Asilomar Conferences brought together experts from bioethicists and scientists to stakeholders and policymakers to discuss the social, ethical, and legal implications of DNA and RNA editing technologies, particularly CRISPR-Cas9[29] which allows for the editing of the human genome. Various policies for recombinant DNA and RNA were discussed and the outcomes decided included the creation of meticulous research protocols, cautiousness for germline editing, and the necessity for global cooperation. However, the Asilomar Conferences failed to reach global consensus due to the widely diverse ethical and cultural views present and conflicting opinions.

[29] SLS |SLS, and Henry T. Greely. "Of Science, CRISPR-Cas9, and Asilomar." *Stanford Law School*, 4 Apr. 2015, law.stanford.edu/2015/04/04/of-science-crispr-cas9-and-asilomar/

### United Kingdom's Human Fertilisation and Embryology Authority (HFEA)

One of the most successful attempts to regulate the use and misuse of genetic testing was made by the UK when it established the Human Fertilisation and Embryology Authority (HFEA). The HFEA displays the balance between allowing genetic testing for severe conditions and preventing its use for enhancement rather than disease prevention. It has enforced strict ethical boundaries whilst not approving the use of polygenic embryo screening for complex conditions such as autism or schizophrenia until further scientific research proves its accuracy. The UK's approach successfully allowed strictly necessary genetic testing to occur while considering its citizens' health and the potential risks of the techniques.

### European Convention on Human Rights and Biomedicine

The European Convention on Human Rights and Biomedicine, which is also known as the Oviedo Convention is the only international legally binding instrument in the biomedical field for the protection of human rights. It was aimed at addressing propositions for the ethical application of biomedical technologies while emphasizing the safeguarding of privacy, human rights, and dignity. Its outcomes demanded that genetic testing should only be used specifically for scientific research and medical testing while offering proper counseling and obtaining informed consent. The Convention strictly forbids the misuse of genetic data for non-medical purposes or instances of discrimination such as the selection of favorable traits for future generations.

## Possible Solutions

### Establish strict national regulations and legislation for polygenic screening

Similarly to the UK's HFEA one course of action would be to create guidelines through international cooperation while involving UN bodies such as the WHO and UNESCO. Nations’ governments would closely work with regulatory bodies, such as ethical committees and health authorities which include professionals in the field of ethics and science. The regulatory bodies would be responsible for overseeing the compliance of IVF clinics to the Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT) Act of 1994, while regular examinations could occur to ensure their adherence. However,

potential negative consequences include the possibility that regulation might halt scientific progress and the potential inequitable enforcement of regulations due to nations' varying frameworks. Halting scientific progress in the field of genetic research could decelerate the progress made toward the detection of polygenic diseases such as schizophrenia. It is crucial to minimize its effect by allowing scientific research to proceed while simultaneously creating the framework within which genetic testing will be conducted.

**Promote transparency in consultations**

With the assistance of genetic counselors, health professionals, and UN agencies such as WHO could provide comprehensive and unbiased information in consultations to ensure that parents are able to make fully informed decisions in regard to PGT and PES. Moreover, by introducing mandatory training for genetic consultants we guarantee their comprehension of guidelines and the notion of a penalty in cases of non-compliance. This method, however, may face challenges in the consistent enforcement of regulations, for which we can introduce regular inspections from UN bodies.

**Ban controversial uses of PGT and PES**

Another way of facing the issue would be by implementing the banning of unlawful or unethical uses of PGT and PES, such as selecting desirable traits which risks the introduction of eugenics. An unethical use of genetic testing would be considered in regards to specific cases and would be determined by ethical committees. In practice, this could be executed by strengthening frameworks for bioethics such as the Universal Declaration on Bioethics and Human Rights and the Oviedo Convention, and implementing said regulations through nations' national legal frameworks and enforcing them using enforcement bodies. Moreover, by introducing accreditation for clinics it would discourage the use of genetic testing for eugenics and enhancements. However, a challenge emerging from this course of action could be the difficulty in globally defining what a controversial use of genetic testing is. Through a global conference, we could identify and unanimously agree upon what defines a controversial use such as the selection of desirable traits and gender.

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