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THE ETHICS OF PRESELECTING CHILDREN

PGD, PGS AND PRENATAL TESTING

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What unites these techniques ethically?

- **Controlling** who and what kind of people are allowed to exist in the future.
- **All are immoral according to certain ethical positions** that view attempts to technologically control reproduction and its outcomes as wrong.
- **Who should have the power** to exercise the control, why, and how?
- **Always situated in a societal context with existing power structures**, and competing interests and values with regard to how different kind of people fare and are valued.
- **Historically linked to a long series of attempts of societies to control population growth, composition and reproduction** – more or less involving freedom for individuals to do as they please, mostly not. E.g., compulsory sterilisation policies of the 20th century, regulation of abortion, contraception, marriage, parenthood, etc.



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How do they differ (ethically)?

- **The aim of the control may be direct** (PNT, PGD) **or indirect** (PGS) – ultimate aims may be different (having children with(out) certain features vs. having children at all)
- **Some necessarily involve ethically controversial actions**, such as destruction/killing of embryos and/or fetuses (PGD, PGS), while others may but must not (PNT)
- **Some are more obviously linked to the realisation of their ultimate aim** (PNT, PGD) **than others** (PGS) – major uncertainty to what extent PGS actually improves the success of IVF.
- **Some bring more obvious risks of some parties being disempowered** (PGD, PNT) **than others** (PGS)

Moral Roots: Proposed Aims and Actual Motives

(Traditional healthcare aims

- Cure or prevent disease – **none of the methods can do that)**

Emancipatory aims/motives (most obvious in PGD and PNT for monogenic traits)

- Help a couple/woman to have children (if they want)
 - PGS might do that (if it actually works)
 - PGD/PNT might do that in the sense of overcoming psychological/social impediments (in case of fear of having a child with some condition that may be detected).
- Help a couple/woman to avoid having certain types of children (if they want)

Societal aims/motives (most obvious in broad PNT screening programs)

- Decrease the number of children born in need of care and support
- Saving money

Business aims/motives (obvious in all of the areas, a growing phenomenon)

- Sell reproductive biomedical products and services
- Attract customers within a given reproductive genetic technological market

These aims/motives/values conflict

- The societal aims assume that people make certain choices – **incompatible with the emancipatory aims**
- The societal aims also incompatible with standard conception of health care values
- The emancipatory aims assumes that a lot of resources are spent on promoting well-informed decisions – **probably incompatible with both societal and business aims**
- Business aims only strive to **create a consumer demand** – not obviously valuable for either society or individual people, and possibly destructive.

Two specific ethical issues

- **How free can reproductive genetic decisions really be**, given strong socio-cultural pressures, expectations, and structural inequalities with regard to different kind of people?
 - Classic criticism: No real PGD/PGS/PNT program fulfills the conditions needed for being able to promote freedom even if we assume this to be possible
- **Why should societal resources be spent on PGD/PGS/PNT** rather than social measures aimed to make it less important (a) to have/not have children, (b) to have certain kind of children, (c) other valuable health-related aims?
 - The classic "disability criticism": All use of PGD/PGS/PNT assumes, expresses and perpetuates a view according to which disabled people are less valuable and less important. Especially since the promotion of reproductive freedom by these techniques is a misnomer.



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Recent challenges: business interests and whole genome sequencing

- "Direct to consumer testing" online: via or not via medical professionals and genetic counselling, creates increasing uncertainty of patient's preconceptions and biases when requesting reproductive selective services: **increases need for robust counselling capacities.**
- Innovations coming out of and marketed by private business rather than public medical research: "testing kits", NIPT, Time lapse, PGS ... **No demonstrated benefits to patients interests and freedom, but risk of disappointment and manipulation.**
- Whole genome sequencing: Creating enormous problems regarding where to draw the line on what to test for and why. **Huge threat both to patient freedom, and to the economic viability of testing programs.**

Case in point: The marketing of PGS (2.0) as effective or "promising" in spite of lack of evidence



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COMMENT

Reply to the signatories of the COGEN Consensus Statement

21 March 2016

By Heidi Mortes, Sjoerd Repping & Guido de Wert

Ghent University; Academic Medical Centre, Amsterdam; Maastricht University, the Netherlands

Appeared in BioNews 844

The signatories of the COGEN consensus statement attempt to refute our remarks and concerns about the increased use of preimplantation genetic screening (PGS) by presenting the same low-level 'evidence' they continuously use to advocate the widespread adoption of PGS (BioNews 840). In an attempt to once more explain our concerns, there are three serious issues that we will address again.

First, there is no high-level evidence available that demonstrates that PGS will increase the chance for subfertile couples to achieve a live birth. The few trials that have been conducted suffer from serious design, analysis and interpretation issues (1). Yes, randomised controlled trials (RCTs) have been performed, but a randomised trial of low quality is still a low level of evidence despite the fact that patients were randomised. Also, performing a meta-analysis on these flawed RCTs does not magically result in evidence. Unfortunately, many clinics do not bother to wait for evidence, even though they are aware that evidence is lacking. This is emphasised in a survey published alongside the COGEN consensus statement: while 77 percent of all clinics state that PGS is offered in their clinic, 84 percent of those state that more randomised trials are needed to support the use of PGS.

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Volume 22, Issue 8
August 2016

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The why, the how and the when of PGS 2.0: current practices and expert opinions of fertility specialists, molecular biologists, and embryologists

Karen Sermon ; Antonio Capalbo; Jacques Cohen; Edith Coonen; Martine De Rycke; Anick De Vos; Joy Delhanty; Francesco Fiorentino; Norbert Gleicher; Georg Griesinger; ... [Show more](#)

Mol Hum Reprod (2016) 22 (8): 845-857. DOI: <https://doi.org/10.1093/molehr/gaw034>

Published: 12 August 2016 [Article history](#) ▼

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- **Obvious risk of harming patients** by creating unfounded expectations
- **Patients expect offered methods to be well confirmed**, repetition of the theoretical argument for PGS 2.0 is manipulative unless the lack of actually demonstrated positive outcomes is stressed. But the the conclusion is PGS (2.0) should not be offered.
- **Akin to the quackery** of commercial stem cell banking and "therapy" businesses
- **Danger to the reputation of reproductive medicine in general**: Consistent high standards of what's allowed to be "on the menu" need to be upheld.

Some literature

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