THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

Current and Future Legal Issues in Prenatal and Preimplantation Selection

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Outline

1. Prenatal testing:
   (a) Non-invasive prenatal testing
   (b) The Court of Appeal's decision in *Crowter v Sec of State* [2022]

2. Preimplantation genetic testing as an IVF 'add on'
   (a) PGT-A
   (b) Polygenic risk scores
   (c) Whole genome screening

3. In vitro gametogenesis

Non-Invasive prenatal testing

‘for information only’

‘ … a majority of Australian NIPT users (78.9%) determined the fetal sex through NIPT, and 19.1% indicated that doing so was either the main reason, or of equal importance to other reasons, for engaging in NIPT. They described a variety of reasons for engaging in fetal sex determination. These ranged from: more abstract motivations such as ‘curiosity’ and ‘the more information the better’; perceived practical reasons such as shopping and naming; and a variety of perceived psychological benefits, including maternal–fetal attachment, making the baby ‘real’, and providing time to deal with possible gender disappointment … Overall, the survey respondents indicated a strong disapproval of sex selection via termination of pregnancy, with 92.5% of respondents indicating that they did not view it as morally acceptable.’

Michelle Taylor-Sands, Chanelle Warton, Hilary Bowman-Smart

Regulating non-invasive prenatal testing (NIPT) for fetal sex determination, *Medical Law Review*, Volume 31, Issue 4, Autumn 2023, Pages 521–537

If NIPT is carried out ‘for information only’, should there be any limits on the information parents can acquire prenatally about their future children?

Royal College of Physicians, Royal College of Pathologists, British Society for Genetic Medicine, *Genetic testing in childhood Guidance for clinical practice* (2022)

- Where genetic testing is primarily predictive of illness or impairment in the future, or is predictive of future reproductive risks, a cautious approach should be adopted. Here testing should normally be delayed until the young person can decide for themselves when, or whether, to be tested, because testing in childhood removes the opportunity of the future young person making their own choices

Crowter v Secretary of State for Health and Social Care
[2022] EWCA Civ 1559

Abortion Act 1967 section 1(1)(d)

Subject to the provisions of this section, a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion, formed in good faith—

.... (d) that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

Claimants given permission to appeal on the the ground that section 1(1)(d) breached their rights under articles 8 and 14 of the ECHR (private life/discrimination) on the grounds that the absence of a time limit on termination on the grounds of disability 'perpetuates and reinforces negative cultural stereotypes about people with handicaps by sending a message that their lives are less valuable'.

Crowter v Secretary of State for Health and Social Care
[2022] EWCA Civ 1559

Underhill LJ

… Section 1 (1) (d) is not concerned with the group to which the Appellants belong – that is, those born with serious disabilities – and does not explicitly promote any negative stereotype about them: it is concerned only with the unborn … Their perception, however genuine, that the present state of the law devalues them cannot itself constitute or evidence such an interference: the interference must derive from something in its terms or its effect which, applying an objective standard, unequivocally conveys that message. The existence of a legal right cannot depend solely on the subjective perception of the putative victim.

Peter Jackson LJ

In my view the impact of the legislation on these applicants is not so serious as to amount to an interference…

Many people will know that there is an upper time limit for abortions generally and some will be aware that this does not apply in cases of foetal disability. The fact that the provision appears in a significant statute is in my view relevant. As a vehicle for influencing public attitudes, it is likely to be vastly more influential than, for example, an academic work … I would therefore be inclined to accept that section 1(1)(d) plays its part in contributing towards discriminatory public attitudes …

Abortion Law Reform Act 2008 (Victoria, Australia)

(decriminalised abortion up to 24 weeks (available on request))

Section 5 Termination of pregnancy by registered medical practitioner after 24 weeks

(1) A registered medical practitioner may perform an abortion on a woman who is more than 24 weeks pregnant only if the medical practitioner —

(a) reasonably believes that the abortion is appropriate in all the circumstances; and

(b) has consulted at least one other registered medical practitioner who also reasonably believes that the abortion is appropriate in all the circumstances.

(2) In considering whether the abortion is appropriate in all the circumstances, a registered medical practitioner must have regard to —

(a) all relevant medical circumstances; and

(b) the woman's current and future physical, psychological and social circumstances.

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Preimplantation genetic testing for aneuploidy PGT-A

Ratings for PGT-A	
Rated red for increasing chances of having a baby for **most fertility patients** 	For most fertility patients, the use of PGT-A is rated red for improving the chances of having a baby. This is because PGT-A is a selection tool that often reduces the number of embryos available for transfer. In addition the time to conception resulting in live birth may also be longer. See the sections **What's the evidence for PGT-A?** and **Is this treatment add-on safe?** for more information.
Rated green for **reducing the chances of miscarriage for most fertility patients** 	On balance, findings from high quality evidence shows this add-on is effective at reducing the chances of miscarriage for most fertility patients. PGT-A can be considered where appropriate on an individual basis depending on a patient's personal circumstances and medical history. This does not remove the chance of having a miscarriage entirely, as there are other reasons a miscarriage may occur other than aneuploidy. The **NHS page on miscarriage** has further information on this. Reducing the chance of miscarriage may also not increase your chance of having a baby and using PGT-A may decrease the chance of having a baby. See the sections **What's the evidence for PGT-A?** and **Is this treatment add-on safe?** for more information.

- In some cases viable embryos could be discarded. This is because not all embryos may be suitable for biopsy, or because embryos are reported as mosaic. Mosaic embryos may have a lower chance of pregnancy but there are reports of healthy live births after a transfer of a mosaic embryo.
- It is also possible that no embryos may be suitable if chromosomal abnormalities are detected in all the embryos tested. This would mean that although PGT-A can reduce the chances of miscarriage, it may not translate to an increased chance in having a baby.

Preimplantation genetic testing for polygenic risk scores PGT-P

Human Fertilisation and Embryology Act 1990 Schedule 2

1ZA(1) A licence under paragraph 1 cannot authorise the testing of an embryo, except for one or more of the following purposes—

… (b) in a case where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality,

(2) A licence under paragraph 1 cannot authorise the testing of embryos for the purpose mentioned in sub-paragraph (1)(b) unless the Authority is satisfied—

…

that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition.

Preimplantation genetic testing PGT-P

PGT-P is unlawful for use in the UK as it does not meet the criteria for genetic testing and is currently not backed by evidence from scientific studies.

Pre-implantation genetic testing for polygenic disease (PGT-P)

You should discuss any questions that you may have about PGT-P with your fertility clinic.

PGT-P involves simultaneously identifying the presence of many gene variants to show whether a person has a higher genetic risk compared with others for developing certain diseases.

Current evidence suggests that polygenic risk scores, which claim to estimate your genetic risk for certain diseases, can be interpreted too rigidly. Making healthy lifestyle choices is likely to have a bigger impact on preventing disease than relying on these genetic scores.

Screening embryos using PGT-P is also likely to reduce the number of embryos available for transfer, thereby reducing the chances of having a healthy baby. This is because embryos that would have been healthy at birth may be excluded due to a perceived risk of disease which may never develop.

We are excited to offer this new and exciting genetic test at VCRM. This test is designed for couples who want to screen for multiples disorders at the same time as their PGT-A testing for chromosomal numbers on the embryos. Just like PGT-A, Preimplantation genetic testing for polygenic disorders (PGT-P) is a genetic test specifically designed to screen polygenic, or "many gene" disorders.

- Type 1 diabetes
- Breast cancer
- Type 2 diabetes
- Basal cell carcinoma
- Schizophrenia
- Malignant melanoma
- Prostate cancer
- Testicular cancer
- Heart attack
- Hypercholesterolemia
- Hypertension
- Coronary artery disease

These polygenic disorders may be screened using LifeViewTM PGT-P (from Genomic Predictions).

Who can benefit from PGT-P?

All couples may benefit from LifeViewTM PGT-P. Especially couples already doing PGT-A, already screening their embryos against aneuploidy risk, may benefit from adding PGT-P to their PGT-A. All couples may benefit, but particularly:

- Couples with a family history of a polygenic disorder, such as breast cancer or schizophrenia.
- Couples determined to be at elevated risk for a polygenic disorder by routine adult screening.

- **Limited accuracy**
- **Limited number of embryos**
- **Waste of money/health inequalities**

US startup charging couples to 'screen embryos for IQ'

Heliospect's services were marketed at up to $50,000 for 100 embryos, undercover footage shows

What is genomic prediction and can embryos really be 'screened for IQ'?

Hannah Devlin, Tom Burgis, David Pegg *and* Jason Wilson

Fri 18 Oct 2024 14.04 BST

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Heliospect has worked with more than a dozen couples undergoing IVF, according to undercover video footage. Composite: Alex Mellon for the Guardian: Getty Images/Alamy/Youtube

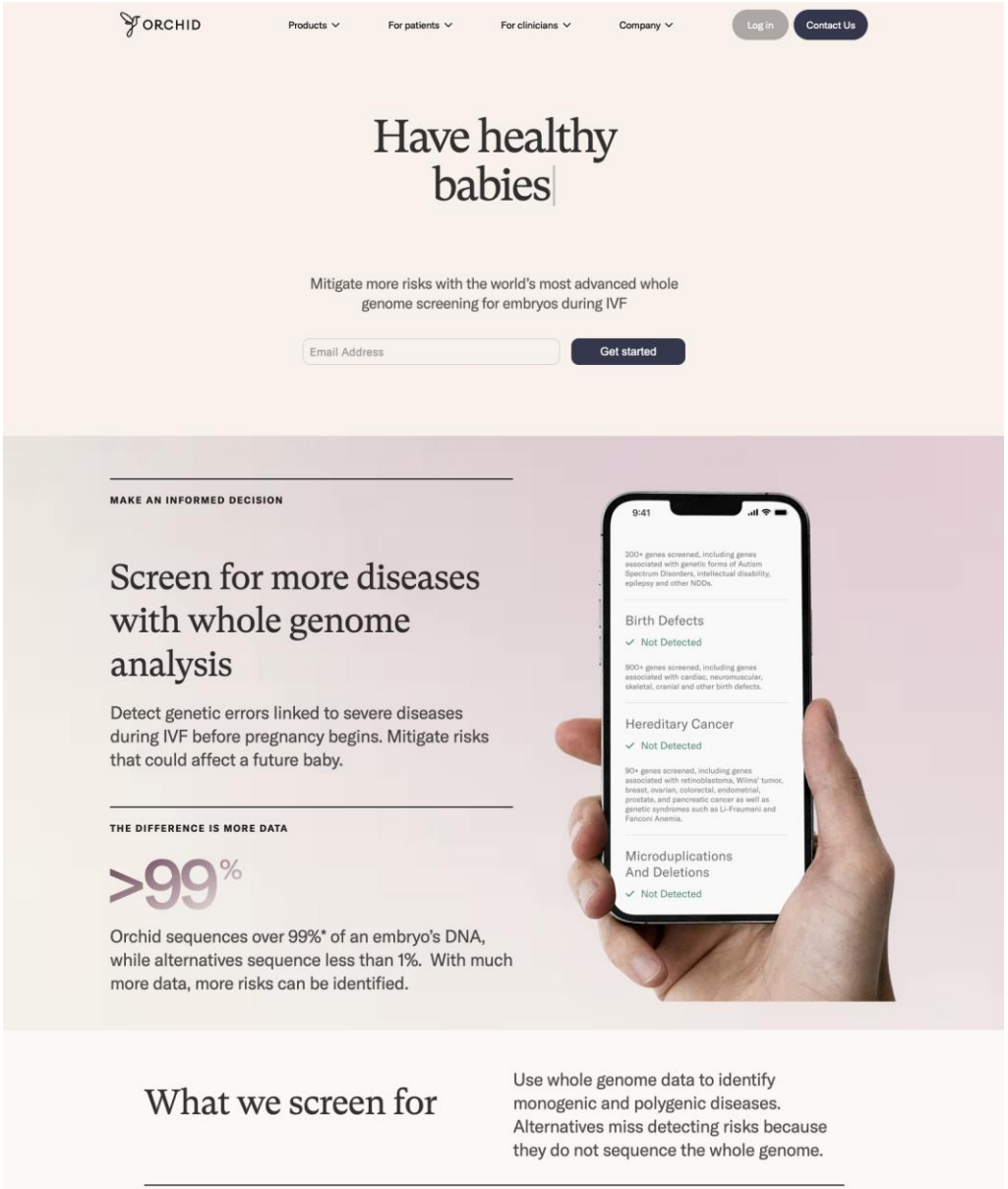
A US startup company is offering to help wealthy couples screen their embryos for IQ using controversial technology that raises questions about the ethics of genetic enhancement.

The company, Heliospect Genomics, has worked with more than a dozen couples undergoing IVF, according to undercover video footage. The recordings show the company marketing its services at up to $50,000 (£38,000) for clients seeking to test 100 embryos, and claiming to have helped some parents select future children based on genetic predictions of intelligence. Managers boasted their methods could produce a gain of more than six IQ points.

Experts say the development represents an ethical minefield.

Preimplantation whole genome screening

- **Limited predictive power**
- **Overwhelming quantity of information**
- **Child's right 'not to know'**
- **Waste of money/health inequalities**



In vitro gametogenesis

From scarcity to oversupply of eggs

Impact on selection?

- Vast quantities of embryos facilitate greater selectiveness with PGT
- In the future, combine IVG with genome editing?
- Is genetic relatedness as a desirable trait different from other desirable traits….