

Participant Information Phase 1

Assessing the validity of a proposed PGT eligibility tool for New Zealand: A survey of attitudes towards PGT in New Zealand

Investigators

Dr Emilie Robertson, Dr Juliet Taylor, Jeanette MacKenzie, Professor Cindy Farquhar, Dr Lynn Sadler and Associate Professor Karyn Paringatai

Background / Rationale

Pre-implantation genetic testing (PGT) is a procedure that allows diagnosis of inherited genetic conditions and chromosomal abnormalities by testing cells from an embryo created using in vitro fertilization (IVF). PGT provides an alternative to prenatal diagnosis, which requires the sampling of fetal cells in utero. PGT can only be used alongside IVF. Currently the guidelines on PGT prepared by the National Ethics Committee on Assisted Human Reproduction (NECAHR) (now replaced by ACART) approve inheritable single gene and sex-linked disorders that have been identified in the whānau and for which there is a 25% or greater risk of an affected pregnancy resulting in a disorder that will seriously impair the individual. PGT is also approved for inheritable chromosomal disorders that have been identified with evidence of serious impairment. PGT requires ethics approval if tissue matching is to be carried out in conjunction with PGT. PGT is illegal for sex selection. The guidelines state that it is the responsibility of the PGT providers in discussion with a clinical geneticist to determine what disorders will cause serious impairment to the individual. This is essentially a self-regulatory approach and can lead to inequity of access. Genetic Service New Zealand Northern Hub and the Northern Region Fertility Service aim to develop and validate a 'PGT eligibility tool' to help determine which conditions meet the criteria for PGT.

Aim of the survey

The aim of phase 1 is to assess the tool's validity and check if the tool covers expected content.

What the survey involves

You will receive a number of statements which we would like you to rank from 1-10 for seriousness. This should take about 10-15 minutes. If you need to leave the survey page, you can return using the link at a later time to complete it. There will be a second survey linked at the end collecting your email should you wish to participate in phase 2. In order to keep phase 1 anonymous, the second survey does not link the email addresses to phase 1 data.

Your Rights

Participation in the survey is completely voluntary and anonymous. You will be asked about your professional role and your ethnicity. You may choose not to answer these questions if you prefer. You are free to decline to participate by not completing the survey. You consent to participating in the study by completing the survey questions. Given the



anonymous nature of the survey you will be unable to withdraw your answers, once submitted. A summary of the findings will be available by journal publication and on the NRFS website.

Benefits of participating in the study

Contribute information in helping shape a new guideline for New Zealand PGT treatment

Risks of participating in the study

If you are personally affected by a genetic disorder it might bring up feelings of sadness and personal and family memories of health problems associated with the condition. Please see below for support available.

What happens after the study?

Data will be stored electronically with no personal identifiers. Only the investigators will have access to the data. Published data will not be identifiable and readers will not be able to identify anyone who participated in the study.

If you have provided contact details to enable participation in phase 2, this information will be stored separately to the survey to ensure anonymity.

Support available

- If the survey raises any concerns for you, please contact us at pgtsurvey@adhb.govt.nz
- If you require Māori cultural support, talk to your whānau in the first instance.
- Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext. 2324. If you have any questions or complaints about the study, you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext. 3204.
- AHREC Chair contact details: For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext. 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.
- Approved by the Auckland Health Research Ethics Committee on 30th May 2023 for three years. Reference number AH23331.

Contact details of research team

Dr Emilie Robertson, Fertility Plus Te Toka Tumai Auckland, emilier@adhb.govt.nz

Professor Cindy Farquhar, Northern Region Fertility Service, c.farquhar@auckland.ac.nz

Dr Lynn Sadler, Northern Region Fertility Service, lynns@adhb.govt.nz

Dr Juliet Taylor, Genetics Te Toka Tumai Auckland, julietaylor@adhb.govt.nz

Jeanette MacKenzie, Fertility Plus Te Toka Tumai Auckland, JMacKenzie2@adhb.govt.nz

