



Participant information sheet: A survey on support needs for preimplantation genetic testing

We are inviting you to take part in a research project. Before you decide whether to participate, it is important for you to understand why the research is being done and what participation involves. Please read the following information carefully and ask us if there is anything you do not understand or would like more information about. Take time to decide whether or not you wish to participate.

Project purpose.

Researchers at the University of Sheffield are carrying out a survey to understand the experiences of people who have used - or considered using - preimplantation genetic testing (PGT-M) in the UK NHS.

PGT-M is a form of IVF in which embryos are tested for an inherited condition before being transferred to the womb, giving couples the option of having a child who has not inherited the genetic condition in their family. We want to understand what that support should look like over the process of PGT-M; we need to hear from people with direct experience to get this right. If you have used PGT-M, are currently going through it, or considered it but decided not to go ahead, we would very much welcome your views. We are asking people to complete a short anonymous online survey, which takes around 10 minutes.

Your responses will directly shape the design of a research study that aims to develop and test a better package of support for people undergoing PGT-M on the NHS. The more people who share their experiences, the more representative and useful our findings will be.

Why have I been chosen?

You have responded to an invitation distributed by a charity or patient support organisation for genetic conditions.

Do I have to take part and how can I withdraw from the survey?

It is up to you to decide whether to participate. If you decide to participate, please complete the consent form in the survey. You can leave the study at any point whilst you are completing the survey by closing the browser window. You do not have to give a reason for why you no longer want to take part. *Your responses will only be recorded if you press 'submit' at the end of the survey.*

You will not be able to withdraw consent after submitting the survey, because you will not give your name so it will not be possible to identify your individual response.

What will happen to me if I take part?

You will be asked to complete a series of questions asking about your experiences of PGT-M, how supported you felt, and what improvements in support you would suggest. You will also be asked to share demographic information. At the end of the survey you will find information about support services should any of the questions prompt difficult feelings. The survey will take around 10 minutes to complete. Please contact the principal investigator (contact details at the end of this document) if you have any questions about taking part.

What are the possible benefits and disadvantages of taking part?

Whilst there are no immediate benefits for completing this survey, your participation will enable us to understand how services can better support people undergoing PGT-M. As a token of appreciation, you will have the option to be entered into a prize draw. There are 3 shopping vouchers, each worth £50, to be won. Winners will be drawn at random after the survey has closed and will be contacted using the email address they provide. You may find answering some of the questions raise difficult feelings and thoughts, if this is the case we provide some contact information for support organisations at the end of this leaflet.

Confidentiality and how will my data be stored?

All information collected about you during the research will be kept strictly confidential and will only be accessible to members of the research team at University of Sheffield. This research will not collect your name. It will not collect your email address unless you opt to share this in order to be contacted about future research or to enter the prize draw. Because your email address is collected through an optional question within the same survey, it will initially be held together with your responses on the survey platform. When the research team downloads the data, your email address will be moved into a separate file and deleted from your survey responses, so that your responses can no longer be linked to your email address. This separate file will not contain a study number or any code linking it to your answers. Only the basic information needed to check whether you are eligible for future research (for example, whether you had PGT-M) will be kept alongside your email address; your full survey responses will not be. Your email address will be used only for the purpose you agreed to and will be securely deleted once it is no longer needed (for the prize draw, once the draw has taken place and any vouchers have been issued). Your responses are anonymous and you will not be identifiable in any reports, publications, or presentations. Any personal information provided throughout the course of the study will be stored securely and held in accordance with the GDPR and the data protection policy of the University of Sheffield.

Data generated as part of this research will be copyrighted to the University of Sheffield. Data will be stored in the University of Sheffield X drive, where it will be encrypted and backed up. Survey data will be stored for a period of 3 years following completion of the project. During that time your data may be used for future research and learning.

What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice:

<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

We also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes' (Article 9(2)(j) UK GDPR).

What will happen to the results of the research project?

We will analyse the results to better understand people's experiences of support around PGT-M, and identify if there are any consistent patterns of how we can improve services. Results of the research are likely to be shared with audiences including other researchers, and healthcare professionals, in peer reviewed journal articles, conference presentations, and through other forms of dissemination.

Who is organising and funding the research?

The University of Sheffield is responsible for organising and funding the research.

Who is the data controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's ethics review procedure, as administered by the School of Medicine and Population Health.

Wellbeing support

If completing this survey raises concerns about your own wellbeing, we encourage you to seek support. The following resources are available to you.

Your GP or occupational health service can provide advice and support regarding mental health and wellbeing. If you are in the UK, the Samaritans provide free, confidential support 24 hours a day, 7 days a week, by telephone on 116 123. Mind, the mental health charity, offers information and guidance at www.mind.org.uk. If you are based outside the UK, please contact your national mental health support service or your institution's occupational health provision.

What if something goes wrong and I wish to complain about the research?

If you feel that you have been mistreated or were upset by anything in the study, please contact Dr Alisdair McNeill (details provided below), who will be able to handle your complaint. If this is not handled to your satisfaction, you may contact the head of the Division of Neuroscience, who will escalate the issue accordingly. If you have a complaint with regards to the handling of your personal data, information on how to raise a complaint can be found in the university's privacy notice.

<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

Contact details for further information:

Dr Alisdair McNeill, Principal Investigator

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