ECHO-S NIPT study

Participant Information Sheet

Version 2, 28/07/2026

Thank you for taking the time to read this information and consider participating in our research study.

This information sheet is for **Healthcare Professionals** involved in the delivery of non-invasive prenatal testing (NIPT) through the NHS in Scotland.

ECHO-S NIPT study: Experiences and perceptions among healthcare professionals and women of NIPT in Scotland

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You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others, such as your friends and relatives, if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Thank you for reading this.

Chief Investigator: Dr Rute Vieira, rute.vieira@abdn.ac.uk, University of Aberdeen

Study team contact: Dr Elinor Sebire, elinor.sebire2@abdn.ac.uk, University of Aberdeen

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Summary

1-hour online interview. A small number of in-person interviews will take place.

At a time that suits you

£25 LoveToShop voucher to say thank you

You will have the chance to talk through this information sheet with a researcher and ask any questions before you sign a consent form and take part in an interview.

1. What is the purpose of the study?

In September 2020, NHS Scotland introduced non-invasive prenatal testing (NIPT) as a new screening test for Down's, Edwards' and Patau's syndromes.

Work has already been done to assess the effectiveness of this change in reducing the number of invasive procedures performed. Less is known about the effect this has had for the staff involved in the care of women and individuals who have experienced pregnancy. This study aims to understand the experiences of healthcare professionals who are involved in delivering antenatal trisomy screening within the NHS in Scotland. The study will also interview women and individuals who have experienced pregnancy about their experiences of NIPT since its introduction in Scotland.

The study will run until April 2028, and participants will be required to have one interview with a member of the research team. The interview will last approximately one hour and will be conducted online or over the telephone if preferred. A small number of Aberdeen-based in-person interviews will take place. If you are local to Aberdeen city or Aberdeenshire please let us know and we can arrange for an in-person interview if this is preferred. Your local travel to/from the interview will be reimbursed to you. Please see section 4 for more information.

2. Why have I been chosen?

You have been invited to participate in the study because you meet our study inclusion criteria. This means you:

1. Are a maternity Healthcare Professional (HCP) involved in offering or delivering antenatal screening (including NIPT) through the NHS in Scotland (including, but not limited to nurses, sonographers, midwives, consultants, genetic counsellors) since 28th September 2020,

If you are not sure if you meet the study inclusion criteria listed above, please feel free to contact our research team by emailing: elinor.sebire2@abdn.ac.uk, and we will be happy to help.

3. Do I have to take part?

No. It is up to you to decide whether to take part. You will be given the opportunity to discuss this information sheet with the researcher before taking part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form for the collection of your details and to be interviewed. You can initial each statement and sign it by typing your name. The signed consent form is to be returned to the researcher via email for the research team to verify and sign. If you are having your interview in-person, then you can return the signed consent form to the researcher before the start of the interview. In both cases, the researcher will go through each statement in the consent form before the interview begins to make sure you understand and

agree to each part. If you decide to take part, you are still free to withdraw at any time and without giving a reason. You may withdraw your data up until the end of the study (April 2028). After this point, the pseudonymisation key linking your identity to your interview will be deleted, and it will no longer be possible to identify or remove your data. If any of the findings from the study are published before the end of the study period it will not be possible for your data to be deleted any longer.

Please note, we will remove your personal information from the written record of the interview once the interview is over and replace it with an ID number (called 'pseudonymisation'). We will keep the personal details linked to this ID number separately until the end date of the study (April 2028).

4. What will happen to me if I take part?

If you choose to take part in this study, you will be invited to an online interview with one of the research team. This will take place on Microsoft Teams (you do not need an account with Teams/Microsoft to join the interview). This will last approximately one hour and will ask you questions about your experience and views of NIPT offered in the NHS. You will only need to attend one interview. A telephone interview can also be arranged if you would prefer this. A small number of interviews will be conducted in-person.

A recording of the interview will be used to create a written document of what was said in the interview. This will be done using University of Aberdeen computer software (Panopto). The audio recording will then be deleted after the transcript has been written. You won't be directly contacted by the research team after the interview unless we need to check your responses or arrange delivery of your voucher. You may wish to read any reports and findings that come from this study. We will make these available on the study webpage: https://www.abdn.ac.uk/iahs/research/specialist-collaborations/nipt-downs-syndrome/

Your interview document will be given a unique ID number and we will remove your personal identifiable information (it will be 'pseudonymised'). The personal details we have removed (such as your name and email address) will be stored in a separate folder and then deleted from our database after the study ends (April 2028). We will store the interview document (without your personal details) securely in a University of Aberdeen secure folder for up to 10 years, following the university policy.

Anonymous word-for-word quotes from your interview may be used in research outputs such as publications and presentations.

As a token of appreciation for your time, you will receive a £25 LoveToShop voucher after completing the interview.

For those travelling for an in-person interview (participants living in Aberdeen City or Aberdeenshire only), we will refund your travel cost to and from the interview site. Travels costs will be refunded for public transport (bus or rail) or personal car travel. The Car Mileage rate is 55p per mile (fuel only), with claims being limited to the cost of standard rail travel for the equivalent journey (in line with the university travel expenses policy). Journey and mileage details must be provided. We will not refund the cost of motoring offences e.g. speeding tickets and parking fines. Taxis will not be reimbursed unless a reasonable method of public transport is not available. Travel by rail should be in standard class. All tickets and receipts should be retained and a copy provided to the research team for claiming travel expenses.

You may withdraw your data up until the end of the study (April 2028). After this point, the pseudonymisation key linking your identity to your interview will be deleted, and it will no longer be possible to identify or remove your data. If any of the findings from the study are published before the end of the study period it will not be possible to for your data to be deleted any longer.

5. What are the possible disadvantages and risks of taking part?

Some of the topics discussed in the interview may be sensitive or emotional, particularly if they relate to your experiences during clinical practice.

You do not have to answer any questions you do not feel comfortable with. You can pause or stop the interview at any time.

If you become upset during the interview, the researcher will offer to pause or stop the discussion.

If you feel distressed after the interview, we will provide information about relevant support services (for example ARC - Antenatal Results and Choices, or Down's Syndrome Scotland).

Choosing not to participate, or withdrawing from the study, will not affect your healthcare, employment, professional relationships, or access to services.

6. What are the possible benefits of taking part?

The information we get from this study may help us to recommend changes to how screening is delivered in the NHS, identify staff training needs, and may help

provide better information to women having NIPT screening in the future. It may also direct future areas of research on this topic.

7. What happens when the research study ends?

You will only be asked to participate in one interview. We do not plan to contact you again after your interview unless we need to check your responses or to arrange delivery of your voucher. You may wish to read any reports and findings that come from this research, which will be made publicly available on the study webpage (https://www.abdn.ac.uk/iahs/research/specialist-collaborations/nipt-downs-syndrome/).

8. What if something goes wrong?

If you have a complaint or concern about any aspect of the research, in the first instance you should ask to speak to Rute Vieira (rute.vieira@abdn.ac.uk) who will do her best to answer your questions. If you remain unhappy and would like to complain formally, you can do this by contacting the University of Aberdeen Research Governance team: researchgovernance@abdn.ac.uk.

9. Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any personal information you provide in your interview (like your name and email address) will be removed from the interview record and replaced with a unique ID number so that you cannot be recognised from it. You will be asked to provide your job role and demographic details during registration and in the interview (such as your age, ethnicity, religion), this is to help us ensure we interview a diverse range of individuals in this study. Your personal information will be kept securely and separately from your interview record. The personal information will be deleted at the end of the study.

All information that you provide will be treated confidentially and no identifiable information about individuals, specific roles, or workplaces will be included in study outputs. Care will be taken during analysis and reporting to ensure that quotes or findings cannot reasonably be attributed to individual participants or specific NHS settings.

We collect this information to conduct academic research, manage the research project and to publish our research findings. The University undertakes and publishes research under its statutory powers. These powers are laid out in the Universities (Scotland) Acts 1858 - 1966.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a study number (ID) instead as mentioned.

The University of Aberdeen is the sponsor of this research. The University of Aberdeen is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- Keeping it in a password-protected Excel file, in a secure folder held on the University of Aberdeen's server that can only be accessed by members of the research team.
- Following your interview, your name and contact details will be removed from the interview document (transcript). Your transcript will be given an ID number instead. Your personal details will be held in a secure file until the end of the study.

Your data will not be shared outside the UK.

10. What will happen to the results of the research study?

The results of this research will be written up as a report for the university and submitted for publication in an appropriate scientific journal and may be presented at scientific conferences. You will not be identified in any report or publication of these results. We will also produce a summary of the research findings for those who took part.

You will be able to find any published materials from this study signposted in the research webpage: https://www.abdn.ac.uk/iahs/research/specialist-collaborations/nipt-downs-syndrome/

11. Who is organising and funding the research?

The research team are based at the University of Aberdeen and have funding to carry out this research through a fund from the Russell Trust called the Roy Weir Fellowship.

12. Who has reviewed the study?

The University of Aberdeen Ethics Committee, SERB, has reviewed this study (ID: 13101949).

13. Contact for Further Information

More information about the previous research done by the team can be found in our website: https://www.abdn.ac.uk/iahs/research/specialist-collaborations/nipt-downs-syndrome/

Research study contact: Dr Elinor Sebire, elinor.sebire2@abdn.ac.uk

If you would like to ask any further questions, please contact the Principal Investigator for this research:

Dr Rute Vieira, email address: r.vieira@abdn.ac.uk

Thank you for considering taking part in this study.