

Participant Information Sheet

Evaluation of NHS Resolutions' Early Notification (EN) Scheme

Information for women, birth partners and other family members

Version 1.2 (18/02/2025)

We would like to understand your experience and views about the Early Notification (EN) Scheme

1 Who is invited to take part?

You have been identified as an individual who has knowledge and experience of the Early Notification (EN) Scheme. This may be because you were involved in the scheme following harm to your baby during childbirth. You may also be a family member of someone with experience of the scheme.

2 Do I have to take part?

Taking part in the project is completely voluntary. We hope you will take part as this will provide helpful insights about the EN Scheme, and its impact on the families.

If you change your mind about taking part, you can withdraw at any time during the interview without giving a reason. You will have the opportunity to withdraw from the study until approximately 14 days after completion of the interview. There will be no adverse consequences from a decision to withdraw. Beyond 14 days after participation, data may have been anonymised, and withdrawal may not be possible.

3 Who is running this project?

The Healthcare Improvement Studies (THIS) Institute at the University of Cambridge is leading this project. You can find out more about THIS Institute here:

<https://www.thisinstitute.cam.ac.uk/> .

The study is funded by NHS Resolution, and the findings will be reported to NHS Resolution to inform future development of the EN Scheme. NHS Resolution has no involvement in analysis and will have no access to identifiable data.

4 Who has reviewed this project?

The study was submitted for ethical review at the University of Cambridge, and reviewed by the Cambridge Psychology Research Ethics Committee on 03.03.2025, ref number PRE.2025.007.

5 What will happen and how will I be involved?

If you would like to participate, you will be interviewed by a researcher via a video-call or phone. The interview will last around 60 minutes (or less if you prefer) and will be recorded. Other family members can attend the interview for support, or if they wish to join you in sharing their perspectives on the EN scheme.

To participate, you need to provide consent. We use online consent forms. You have received a link to it in an email, you may also access it at the end of this page.

During the interview, the researcher will ask you about topics including:

- Your experiences of the EN Scheme
- Outcomes of the scheme for your family
- How the scheme could be improved

The recordings of the interviews will be transcribed and analysed. All transcripts will be fully anonymised to remove any information that could identify people or places. The anonymised transcripts will be stored on the University of Cambridge secure servers.

All personally identifiable data, including the online consent form we obtain from you, the ID that links you to the anonymised transcript, and the recording of our interview, will be stored on the University of Cambridge safe haven (an ISO 27001 certified platform) until 24 months after the study ends to minimise the risk of any data being stolen or lost.

6 What happens to my answers?

Your anonymised answers will be analysed along with the answers from all other participants and will be used to develop a summary of findings that will be reported to NHS Resolution. This summary of findings will then be used to create a final report. Findings from this project may also be published in academic journals and presented on THIS Institute's and NHS Resolution's websites.

This is an independent evaluation, being conducted by THIS Institute. NHS Resolution will not be involved in analysing the data, and no identifiable data will be shared with NHS Resolution. You will not be identifiable in any findings that are published, and any quotations from interviews used in reporting will be anonymised.

General information about how the University uses personal data can be found here <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>

7 What are the benefits of this study?

There are no direct benefits to you from taking part. However, the results of the study might help to refine the EN Scheme by contributing your views, experience, and suggestions for improvement.

8 Are there any risks?

We know that for some participants talking about personal experiences of being on the Early Notification (EN) Scheme might be upsetting. To address this and support you during the interview, our experienced interviewers will be alert to signs of distress, and will support you in an appropriate and sensitive manner. This may include pausing or stopping the interview, and helping you to access appropriate support and follow-up if necessary. You are also free to withdraw from the study at any time without giving any reason.

In the unlikely event that you disclose information during an interview with an interviewer that suggests care that may not be safe, or that you may be at risk of harm to yourself or others, then the project team will take appropriate action. If appropriate, this may include contacting relevant bodies or authorities. Wherever possible this would be done with your permission and/or that of the individual(s) involved. However, if this is not possible, confidentiality will be breached if necessary.

We will keep the information you provide confidential, unless you disclose concerns about malpractice or professional misconduct by NHS staff. In such cases, we may need to report this information to the relevant authorities as part of our ethical responsibilities. We will inform you if such action is necessary, wherever possible.

9 Get in touch

If you have any questions or concerns about anything to do with the study, you can contact Gizdem Akdur at gizdem.akdur@thisinstitute.cam.ac.uk.

For any complaints or concerns

If you have a complaint about any aspect of the project, please contact the director of THIS Institute, Prof. Mary Dixon-Woods, by email on mary.dixon-woods@thisinstitute.cam.ac.uk. If you are not happy after that, you can contact the Data Protection Officer at dpo@admin.cam.ac.uk.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

The study team

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