

Participant Information Sheet (V1.1 19/10/2021)

We would like to invite you to take part in our research study, which is part of a PhD project funded by the White Rose Consortium. Joining the study is entirely your choice. Before you decide whether you would like to take part, please read the following information. Please feel free to talk to others about the study and to contact Hollie Henderson if you have any questions.

What is the purpose of this study?

An exciting new family of projects, known as Born and Bred in (BaBi), is being developed across the region, to help us learn more about how families, in our area and beyond, can live healthier, happier lives. Each local area has set up their own project, which gains consent from women during their pregnancy to link information routinely collected as part of everyday services about themselves and their baby. BaBi builds on the success of Born in Bradford 4 All (BiB4All), where Bradford is supporting other local sites to develop their projects. The term linked data refers to the linking of individual information from more than one source for the purposes of research.

The aim of this study is to explore how we can best engage with and support those working in the field of early life health to make use of this linked data to inform decision-making. This is important as we want to make best use of research produced as part of the BiB4All and BaBi project to improve services for families locally.

Who is doing the study?

Hollie Henderson, a PhD student located in the Department of Health Sciences at the University of York will be carrying out this study, in partnership with the Bradford Institute of Health Research. This will be under the supervision of Professor Kate Pickett, Professor James Wilsdon and Sally Bridges. This research is funded by the White Rose Consortium and is part of the National Institute for Health and Care Research Yorkshire and Humber Applied Research Collaboration.

Why have I been asked to participate?

You are invited to take part because you are a decision-maker working in the field of maternity, perinatal and early life health, in a local area which is part of the BaBi project or are involved in the administration of a local BaBi project. We are inviting approximately 20 participants like you to take part. Your responses will be used to design a toolkit to support the BaBi research teams to engage in activities that allow their research to be relevant to decision-makers.

Do I have to take part?

It is entirely up to you to decide whether you would like to take part. If you have any questions, you are welcome to talk to Hollie Henderson, contact details will be provided at the end. If you do decide to take part, you will be given this information sheet to keep and be asked to sign an online consent form. We hope that as many decision-makers as possible take part as this will help ensure a range of views are included.

What will be involved if I take part in this study?

If you do decide to take part, contact Hollie Henderson to arrange a convenient time for you to attend an online interview held over Zoom. The interview will take no longer than 60 minutes and, with your permission, will be recorded via Zoom and on a Dictaphone. This will enable the discussion to be typed up in writing and ensure your views are fully captured. This recording will only be accessible to the research team supporting this project and will be destroyed after the recording has been typed up in writing. You can also take part via a telephone call if this is preferred. During the interview you can ask any questions about the study. You will be asked about your perspectives towards linked data from a consented cohort such as BaBi, its uses for early years decision-making and ways that could help support you to use research produced using this linked data in your decision-making. We also want to hear your views about how we can best engage you in the BaBi project so that you get the most out of the research that is produced. Once the data are analysed for the project, we may contact you again to ascertain your views on the findings and outcomes of the study. This will occur within six months of the interview.

What are the advantages or benefits of taking part?

There are no direct benefits to you taking part in this study. Any benefits will be indirect as a result of helping to inform the development of a toolkit that will engage with and support early years decision-makers to make use of linked data research to help families locally.

What are the disadvantages or risks of taking part?

We do not anticipate that there will be any disadvantages of taking part in this study. Your employment will not be affected by your decision to take part or not in the study.

In the reporting of the results, individuals will not be identified, but job roles will be described. Therefore, there are some instances where identification of participants is possible (e.g., where only one person fulfils that professional role). Further precautions will be taken to reduce the risk of identifying individuals such as no quotations directly attributable to a participant will be included and generic job descriptions will be used.

How will the information and personal data I give be used?

We will need to use information from you for this research project. To safeguard your rights, we will use the minimum personally identifiable information possible.

The information that we collect for this research will include:

- The information from our interview with you, which will be typed up in writing by the research team.
- The information from your completed electronic consent form.
- Your name and contact details. These details are collected for the purpose of arranging and carrying out the interviews and to contact you with the results, should you wish to be kept informed.

We will use your personal information only to do the research. Contact details will be destroyed following the interviews, unless you wish to be kept informed of the study findings, then your details will be destroyed following the completion of the final report. Other authorised individuals may check your records to make sure that the research is being done properly.

Your name and contact details will be kept separate from the other information that we obtain from you for this research. Your research records will contain a pseudonym (false name) instead, so you are not directly identifiable when we use your data in our research.

Your name, contact details and research records will be stored electronically on secure University of York approved storage. Access to this information will be restricted to authorised persons only. We will keep all information about you safe and secure.

For the purposes of obtaining consent to take part in this study, your data will be stored online via Qualtrics and on the secure University of York server. Please use the following link to view the privacy statement: <https://www.qualtrics.com/privacy-statement/>.

Once we have finished the study, some of the data will be kept and stored securely for ten years. This will enable us to complete our publications and reports. After this time, it will be securely destroyed. We will write our reports in a way that no-one can work out that you took part in the study. The data may also be shared with other researchers to conduct further related research, which is subject to approval.

What are my choices about how my information is used?

The University of York is a publicly funded organisation that conducts research to improve health and healthcare services. In legal terms, we are using your information for this research as part of 'a task in the public interest'. The ability to change the data that we have collected, however, is limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you decide to take part and then later change your mind, you can withdraw from the study without giving a reason by contacting Hollie Henderson. You may request that your data is not used in the study up to 28 days after the interview. We will destroy your data

upon this request unless you give your permission for the research team to retain this. After this time, data gathered may have started to be analysed and used in the study findings. Any information that has been used in the study findings cannot be withdrawn. This would not affect your legal rights.

Where can you find out more about how your information is used?

All data will be handled in accordance with the General Data Protection Regulation (GDPR) principles. To find out more about GDPR please use the links provided:

<https://www.york.ac.uk/records-management/dp/>

<https://www.york.ac.uk/records-management/dp/guidance/gdprcompliantresearch/>

<https://www.york.ac.uk/records-management/dp/your-info/generalprivacynotice/>

You can find out more about how we use your information:

- At <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/>
- At <https://www.york.ac.uk/healthsciences/research/trials/trials-gdpr/research-participants/>
- by sending an email to Hollie Henderson
- by emailing the University of York's data protection officer on dataprotection@york.ac.uk

Will my taking part in this study be kept confidential?

If you decide to take part in the study, what you tell us will be kept confidential. No one outside the research team will know that you have taken part in the study.

We will write our reports in a way that no-one can work out that you took part in the study.

Data collected for the study may be looked at by authorised persons who are organising the research. Data may also be looked at by other authorised people to check that the study is being carried out correctly. All have a duty of confidentiality to you as a research participant.

The only time we would break our duty of confidentiality is if we are worried that you – or someone else – was being, or was likely to be, harmed. If that happens, we will talk with you about it.

What will happen to the results of the study?

Once all the interviews have been typed up in writing, they will be analysed by the research team, and a summary report will be sent to you before being disseminated more widely amongst the BaBi Network and the Yorkshire and Humber Applied Research Collaboration. You will have the opportunity to comment on the results before they are shared more widely. The findings will then be written up for publication in peer reviewed journals and may be presented at scientific conferences, so that other researchers can learn from our

findings. Data will be treated confidentially and any output resulting from this study will only report data that does not identify individual participants.

One way we can get the most benefit from this work is to make the study data available to researchers for related research at the end of this study. The study data may be reused by the research team or researchers in other institutions but will not be used or released in such a way that you could be identified. Applications to reuse the data once the project is completed will be reviewed by the Born in Bradford Executive Committee.

Who has reviewed and approved this study?

The study has been reviewed and approved by the University of York's Health Sciences Research Governance Committee reference: HSRGC/2022/488/A.

Who do I contact for more information about the study?

If you have any questions or would like more information about the research, please contact Hollie Henderson. You can do this by *insert contact details*.

Who do I contact in the event of a complaint?

If you would like to talk to someone about a complaint, you can contact Sally Bridges, the lead supervisor for this research, by email: Sally.Bridges@bthft.nhs.uk.

The University of York is the data controller for the information collected for this research, which means we are responsible for looking after your personal information and using it properly. If you are unhappy about the way your personal data has been handled, you have the right to complain to the University's Data Protection Officer at dataprotection@york.ac.uk; if you are still unsatisfied, you have a right to report concerns to the Information Commissioner's Office at www.ico.org.uk/concerns.

Thank you for taking the time to read this information sheet and considering whether to take part in this study.