

BORN AND BRED IN (BaBi): York

**A data linkage cohort study of babies born in York and their mothers/
birthing parents: Information for pregnant women/pregnant people**

What is BaBi York?

This is a project being run by York & Scarborough Teaching Hospitals NHS Foundation Trust and is part of a group of BaBi research projects all about families and children to help us to learn more about how families in our area and beyond can live healthier, happier lives.

How does BaBi York work?

When you see your midwife, they will invite you to become part of the study. If you agree to take part, health researchers will join together lots of data about you and your child so that we can look at ways to improve health, care and services through research and planning in York and beyond. We are asking everyone who is pregnant in York to join the project.

Why do BaBi York want to use my information?

By linking information from both your patient records and your child's patient record, we can build up a much clearer picture of people's lives and answer questions that may help to improve health, care and services through research and planning. Your information can help us begin to explore questions like:

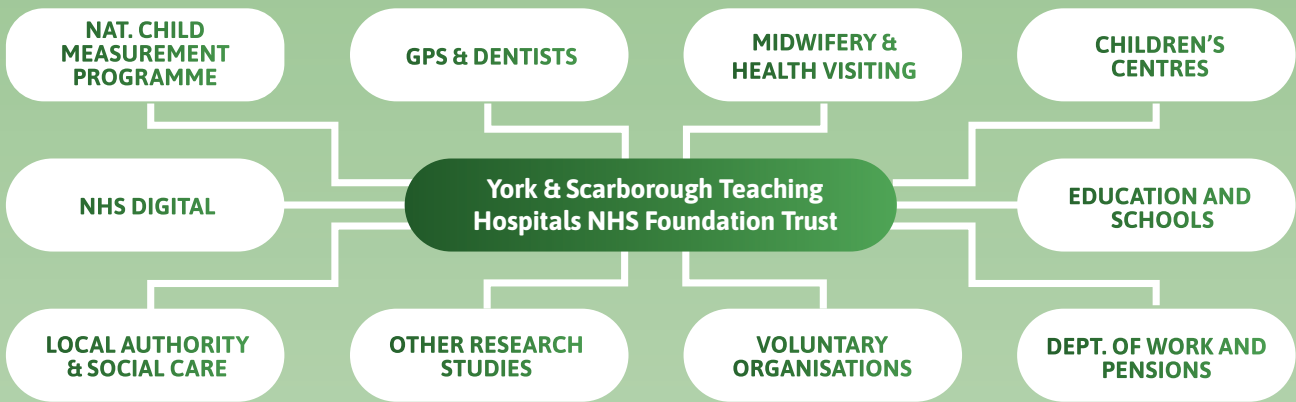
- Are there relationships between things that happen in pregnancy and children's future health?
- How many children in our area have asthma? Are children in some areas more likely to get asthma than children in other areas?
- How common is postnatal depression or diabetes in pregnancy? What could be done to help prevent depression or diabetes and provide support for the family?



What information do BaBi York want to use?

Lots of organisations regularly collect data about the services they provide to you or your children; this is known as routine data. The NHS keeps health records so they can provide health services to you. Social Care keep records about services they provide to you and your family. Education organisations keep information to help them to provide services for your children in schools and so they know what they achieve. All of this information is collected electronically and stored separately on different systems.

The diagram below shows some of the different organisations that we will contact to link information from your patient record and your child’s patient record, or to help us to contact you in the future.



How will BaBi York get my information?

We would like to provide some personally- identifiable details such as name, date of birth, address and NHS number to each of these organisations so they can send us data back about you and your child regularly to get a more complete picture of people’s health and lives. This will be sent using a secure transfer system to keep your information safe.



How will BaBi keep my information secure?

BaBi York is based at York & Scarborough Teaching Hospitals NHS Foundation Trust. All data will be stored securely there and will be treated confidentially. Our systems are password protected and very secure. We will keep information that might identify individuals (such as name and address) separate from other information about participants. Only a very small number of authorised people will have access to any data that identifies you, like your name and address. These include members of the team involved in linking your data together and those involved in keeping you up to date about the study. The researchers who will analyse the data to answer research questions won’t have access to your personal data as we will remove the information that identifies you so they won’t know it’s you and it’s anonymous. Anonymous data will be used for research and service planning. As we want to look at how people’s lives and health change we will keep your information and build on it over time.

How will my information be used?

Your information will only be used for research and service planning. Any sensitive information from BaBi will only be made available to researchers who have relevant scientific and ethics approval for their planned research under restricted access arrangements which make sure that the information is used responsibly and safely. Personally-identifiable information such as name and address are never included in the results and no individual can be identified from the research we publish.

BaBi York will also use your contact details to keep you up to date with the study and to let you know about other relevant research studies that are happening that you may wish to be involved in.

How can I find out what my information has been used for?

We will publish our findings in journals and on our website www.research.yorkhospitals.nhs.uk/babi-study. It won't be possible to identify you in any of the findings because the data used is anonymous. You can also get in touch with us using the contact details below if you would like to know more or have other questions.

We will not send you any individual results from any of the research in the study. This is because we are looking for patterns in the data of thousands of participants and not looking at individual people.

Why should I take part?

Taking part is entirely voluntary and it is up to you whether you decide to join the project. There is no long questionnaire to complete or samples to give, just your permission to allow us to access your data. While there is no direct benefit to you or your child in taking part, we hope that we will learn from all of the information we do get and this will help us to improve health, care and services through research and planning for everyone in York. This might be through improving the way health and care services are delivered in the future or finding new relationships between our genes and health.

What if I don't want to take part?

We won't take any data about you or your child until you have told us that we can. Your midwife will ask you whether you would like to take part at one of your appointments. If you don't want to take part, just let them know. It won't affect the care you receive.

What if I change my mind?

You can change your mind at any time. If you decide to join the project when you speak with your midwife and then later change your mind you can contact us and let us know using the details below and we will not collect any further data from you or your child. This won't affect the care you receive.



More Information

There is more information available about the project on our website

www.research.yorkhospitals.nhs.uk/babi-study

or you can get in touch using the details below. There is also more information on how we use your data online here:

www.yorkhospitals.nhs.uk/about-us/information-governance/privacy-notices/

If you would like a printed copy of any of these documents please email or call us to request one.

Get In Touch

If you would like to contact us about the project or to make a complaint, please contact us by:

Email: Yhs-tr.babi@nhs.net

Write to us:

R&D Department, LARC
York & Scarborough Teaching Hospitals NHS Foundation Trust
Wigginton Road
York YO31 8HE

Call us:

077342075883

Patient Advice Liaison Service (PALS) Contact Details:

Email: yhs-tr.patientexperienceteam@nhs.net

Translations

Written copies of this leaflet are available in Urdu, Bangla and Slovak. We also have audio versions in Urdu, Bangla and Slovak and a video summary in English, Urdu, Bangla and Slovak. If you would like this information in any other language please contact us.

Scan the QR code below for access to this leaflet, and audio and/or video versions through the BaBi York website:

www.research.yorkhospitals.nhs.uk/babi-study



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