



Bradford Teaching Hospitals
NHS Foundation Trust

Born in Bradford (BiB):

A data linkage cohort study of babies born in Bradford and their mothers
Information for pregnant women

What is BiB?

This is a project being run by Born in Bradford (BiB) and is part of a family of research projects all about families and children in Bradford. Between 2007 and 2010 families having babies in Bradford were asked to join BiB to help us to learn more about how families in Bradford can live healthier, happier lives.

How does it work?

When you see your midwife, she will ask for your consent to become part of the study. In it 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 Bradford. We are asking every pregnant woman in Bradford to join the project.

Why do BiB 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:

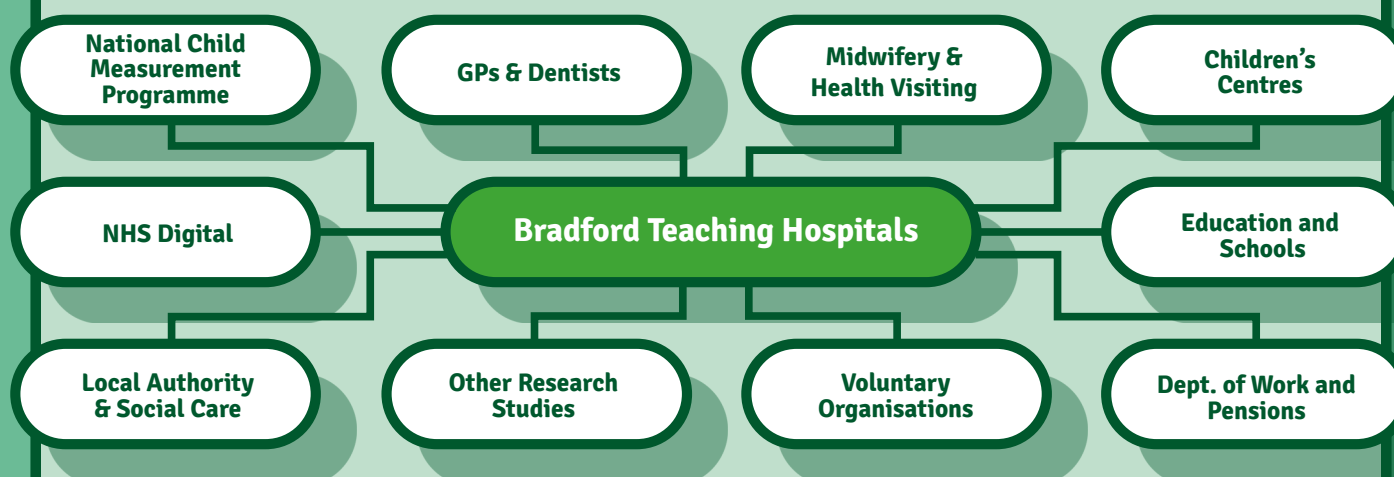
- Are there relationships between things that happen in pregnancy and children's future health?
- How many children in Bradford have asthma? Are children in some areas more likely to get asthma than children in other areas?
- How many mums in Bradford experience postnatal depression? What could be done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



What information do BiB 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 or to help us to contact you in the future.



How will BiB 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 BiB keep my information secure?

BiB is based at Bradford Teaching Hospitals NHS Foundation Trust. All data will be stored securely there and will be treated confidentially. Our systems at the hospital are password protected and very secure. 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 will only be made available to researchers 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 do. BiB will also use your contact details to keep you up to date with the study and to let you know about other 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

<http://www.borninbradford.nhs.uk/>

You can also get in touch with us using the contact details on the back page if you would like to know more or have other questions.

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 what 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 Bradford.

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 on the back page and we will remove you and your child from the project. This won't affect the care you receive. You can decide whether you are happy for any data that has already been collected to remain in the study or whether to have all of your data removed. We will retain your NHS number and hospital number in order to prevent your data being added back into the study.

More information

There is more information available about the project on our website

<http://www.borninbradford.nhs.uk/>
or you can get in touch.

Get in touch

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

Email: borninbradford@bthft.nhs.uk or

Write to us: Born in Bradford Office Bradford
Institute for Health Research Bradford Royal
Infirmary Duckworth Lane Bradford, BD9 6RJ

Telephone: 01274 364474

Translations

Written copies of this leaflet are available in 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 card below for access to this leaflet, audio and/or video versions through the Born in Bradford website.

<http://www.borninbradford.nhs.uk/>

