



Born in Bradford Information sheet for BiB cohort at 18– Routine Data Linkage V2

Born in Bradford would like to continue to link to data collected on you from other organisations.

Lots of organisations collect data about the services they provide, known as routine data. The NHS keeps health records, social care services track the support they provide to families, and schools record academic progress. If your parents signed up to the BiB study when you were born, we previously asked their permission to this. Now you are 18, we would like to continue to link to your records.

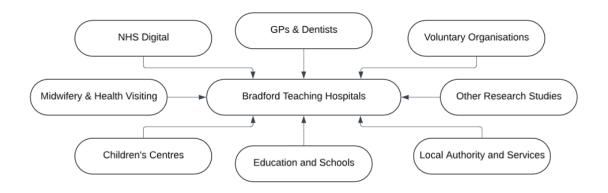
Why does BiB need to link to this data?

By linking information from records, 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:

- How many young people in our area have allergies? Are some people more likely to develop allergies than others?
- What was the impact on health, wellbeing and education of the pandemic for this generation?
- How does mental wellbeing in adolescence affect later mental wellbeing? What could be done to help prevent mental ill health, and provide support?

What information does BiB want to use?

The diagram below shows some organisations we may contact to link information from your records or to stay in touch in the future.



How does BiB get information about you?

We will share some personal details, like name, date of birth, address, and NHS number, with the organisations above. These groups will send back the routine data they have for you. This data will be securely transferred to keep your information safe.

Doc100_Routine data linkage for BiB cohort in birthday card v2 15.05.25

How does BiB keep my information secure?

BiB is part of Bradford Teaching Hospitals NHS Foundation Trust, where all data is securely stored and treated confidentially. Our systems are password-protected and very secure. Identifiable information (like names and addresses) will be kept separate from other data, and only a small group of authorised staff will access this information. These staff include those linking data and those updating you about the study. Researchers will not have access to personal details, as we will remove them to keep the data anonymous. The anonymous data will be used for research and planning services. Since we are studying long-term changes, we will keep the information and build on it over time, likely to be at least 30 years.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Bradford Leeds Research Ethics committee [Ref: 21/YH/0261, date: 22.12.21]. The research is funded by the Wellcome Trust and is sponsored by Bradford Teaching Hospitals NHS Foundation Trust (BTHFT).

Will the use of your data meet UK GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow data protection law rules set out in the UK GDPR and the Data Protection Act (2018). All research using your <u>personal data</u> (information that identifies you as a living person) must follow these rules, including research using your confidential data. You can find out more about how Born in Bradford meets these rules on our website at https://borninbradford.nhs.uk/privacy-policy/.

How is my information used?

Your information is only used for research and service planning. Researchers must have ethical approval to access sensitive data, and their access is strictly controlled. No personal information like names or addresses are ever included in any results, so you cannot be identified from the research we publish. BiB may also use your contact information to update you about the study or tell you about other relevant research opportunities.

What are the benefits of taking part?

Participation is voluntary, and it's up to you to decide. We hope this research will help improve health and wellbeing services for everyone in Bradford.

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

We will publish our findings in journals and on our website, www.borninbradford.nhs.uk. The data used will be anonymous, so nobody can identify you from the findings. You can contact us anytime for more information using the details below. We do not provide individual results because we focus on patterns across thousands of young people rather than individual cases.

What happens next?

If you are happy for us to continue to collect this information, you don't need to do anything.

What if I don't want to take part?

Please contact us by calling the BiB project office on 01274 274474 to withdraw from Born in Bradford.

What if I change my mind?

You can change your mind at any time. Simply contact us on the number below. You can also find this in the 'contact us' tab. This will not affect the care you receive or your participation in other BiB projects.

Where can I go to find out more or make a complaint?

If you want to find out more, or have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions:

- By sending an email to ageofwonder@bthft.nhs.uk
- By calling the BiB project office on 01274 274474

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

- Our website www.borninbradford.nhs.uk
- The Health Research Authority website www.hra.nhs.uk/patientdataandresearch

If you have any further concerns about the use of your data, you can contact the data protection officer for BTHFT (Jennifer Pope) on dataprotectionofficer@bthft.nhs.uk or the Information Governance team on Information.Governance@bthft.nhs.uk.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions Tel: (01274) 274474. If you remain unhappy and wish to complain formally, you can do this by contacting the BTHFT Research and Development team on bradfordresearch@bthft.nhs.uk or Tel: (01274) 383418