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STUDY PROTOCOL

Born and Bred in (BaBi): an efficient, place-based birth e-cohort network

[version 1; peer review: awaiting peer review]

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Abstract

Background

Routine datasets are increasingly used in research to learn more about health and care systems over time. This paper describes the protocol for a novel, multi-site, life course e-cohort embedded in standard clinical practice: The Born and Bred in (BaBi) network. BaBi aims to link routinely collected data for mothers and babies at local and national levels for research and decision-making.

Method

The BaBi network e-cohort uses an active consent process, where trained healthcare practitioners (predominantly midwives) gain consent from pregnant women during their routine antenatal appointments. This is documented in electronic patient records and allows identifiable routine data from multiple health, social care, and educational sources to be linked over a mother and baby's life. Consent to contact is also gathered, providing a platform to approach recruited participants about future research opportunities. BaBi provides a long-term, sustainable, applied research platform that promotes inclusivity in research and transparent use of data.

The BaBi network aims to harness the power of locally linked routinely collected data to help shape local services and to bring together data from local cohorts to create a meta-cohort that can be used to address questions of national relevance.

The model provides opportunities for all pregnant women to take part with no restrictive eligibility criteria, promoting participation from a wide range of diverse and underserved populations. The minimal participant burden, coupled with the embedded consent approach through antenatal services, aims to ensure less systematic bias in representativeness than that seen in more traditional cohort methods.

Plain Language Summary

Information is routinely collected and recorded when people use public services such as health, education, and social care. Increasingly, this routinely collected information is being linked together and used in research to learn about how local services can better meet the needs of the people it serves. The Born and Bred in (BaBi) project is a network of local research groups that ask pregnant women during their routine maternity appointments for permission to link together information that is routinely collected about them and their baby for research. BaBi also asks for permission to contact them about other relevant research opportunities.

This protocol describes how the BaBi network was founded on the success of 'Born in Bradford,' a research project that has followed the health and lives of families in Bradford since 2007. Following the same group of people over time for research is called a cohort study. The BaBi network team designed the cohort study carefully to make sure that as many pregnant women as possible are able to take part.

The first BaBi cohort site was set up in Bradford in 2019, known locally as BiB4All, where all women having maternity care at Bradford Royal Infirmary were eligible to take part. Other local areas were then supported by the BiB4All team to set up the same process in their hospitals, which resulted in the BaBi network.

The first aim for each local BaBi cohort is to link together routinely collected data from multiple sources to build a clearer picture of families lives over time and use this information to shape local services. The second aim is to bring together data from the local cohorts to answer important research questions together across England.

Keywords

Cohort, children, routine data, linkage, network, capacity building, Born in Bradford

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Background

Starting from the moment we are born, data are routinely collected and recorded on how much we weigh, where we live, how we develop and learn, and the state of our health. Pseudonymised routine datasets are increasingly used globally in research to learn more about health and care systems over time^{1–3}.

Many traditional research cohorts have gained consent from their participants to link research data with routine data collected by public services as a means of long-term follow up^{4–6}. However, while traditional longitudinal research cohort studies have been invaluable for advancing our understanding of many epidemiological and social processes, they are resource-intensive and, as a result, limited to a particular window in time⁷. They are also subject to loss to follow-up and participation bias. On the other hand, pseudonymised databases that link routine data for a population have almost complete population coverage but are limited by the inability to link and analyse data across family and household units over time and follow up on the patterns or trends identified in the data. In addition, the use of routine data for research without consent has been identified as a cause for concern, with issues of trust and transparency highlighted by some communities as barriers to participation^{8–10}.

The benefits of linking routinely available data at the local level are being increasingly acknowledged^{7,8,11}. In addition to ensuring that intelligence related to population health is representative, it enables a greater understanding of local population health needs, including whether, how, and for whom commissioned local services are working. Using these types of data to inform local-level decision-making presents a substantial opportunity for the targeted allocation of finite resources.

In 2019, building on the foundations of an existing research cohort, ‘Born in Bradford’¹² (BiB) within the well-established research infrastructure of the [Bradford Institute for Health Research](#), the BiB team established a novel e-cohort called BiB4All to harness the potential of broad ranging routine linked data with active consent. Following the demonstration of feasibility and acceptability, we were approached by other cities across the UK to support the replication of the model. This paper describes the development of a new prospective, longitudinal, multi-site maternal and child cohort study, the Born and Bred in-(BaBi) network.

Aims of the BaBi Network

The BaBi network is an applied e-cohort that aims to:

- 1) Harness the power of routinely collected data from multiple sources and link them together to build a clearer picture of children’s and families lives over time.
- 2) Create a series of electronic routine data cohorts across England that can be used to provide health intelligence and improve quality of care, informing service design and delivery.

- 3) bring together data from the local BaBi cohorts to create a meta-cohort that can be used to address questions of national relevance, common priority, or in rare disease areas.

Methods

Design

BaBi is a prospective longitudinal cohort study. Recruitment to the study is through a highly efficient embedded consent process administered by midwifery teams, which enables identifiable, routine data from multiple health, social care, and education sources to be linked over a mother and baby’s life. Consent to contact is also gathered, providing a platform to approach recruited participants about future research opportunities. The multi-site nature of the network also facilitates a large-scale meta cohort of harmonised datasets across multiple localities with differing characteristics, providing a data environment capable of supporting research questions generalisable at the national population health level to inform evidence-based policymaking.

To achieve the study aims, each local cohort has the following objectives.

- To approach all eligible pregnant women and invite them to join the cohort.
- To train relevant maternity staff to obtain informed consent from women to join the cohort (and be contacted about future research) during routine maternity care appointments.
- To link together a variety of routine data from health, education, social care, and other relevant settings for consented individuals over time.
- To use linked data to explore whether there are patterns in the data that identify poor health and development, including looking for early warning signs that could be used to identify risks.
- To develop a resource for future research on maternal and child health and development.
- To collaborate with the wider network of sites on questions of common interest.

Settings and sites

Each BaBi site is located within a local area in England, UK and is led by a partnership of local services, including National Health Service Trusts and Local Authorities/governments. The founding site was in Bradford, UK. Bradford, a city in the north of England, is the fifth largest Local Authority in England and has a population of >550,000 people¹³. It has a youthful population, with 28.2% of the district’s population aged 17 years or less. There are also high levels of deprivation and ethnic diversity. BaBi Bradford (known locally as BiB4All) opened to recruitment in 2019, and all women in receipt of antenatal care from Bradford Royal Infirmary are eligible to participate. This represents approximately 5,900 women per year. Four further pilot

sites (BaBi Wakefield, BaBi Leeds, BaBi Doncaster, BaBi East London) were initially set up to develop the BaBi network, which is managed through a coordinating centre within BiB4All (part of the Born in Bradford programme and hosted at [Bradford Institute for Health Research](http://www.babinetwork.co.uk/sites)). The BaBi Coordinating Centre coordinates the operations of the BaBi network, including the governance and approval of the protocol and associated documentation. Following the success of the expansion of the BaBi model to the pilot sites, BaBi opened to new sites. At the time of submission, 13 BaBi sites were open to recruitment. An updated list of operational BaBi sites is available at <http://www.babinetwork.co.uk/sites>

Participants

Figure 1 shows a flow diagram outlining the identification and recruitment of pregnant women.

Eligibility

All women who are booked to receive maternity care with a participating BaBi site are eligible to join the cohort on behalf of themselves and their expected child at each eligible pregnancy (i.e., a new consent process is initiated at subsequent pregnancies). Women remain eligible throughout their pregnancy and after their babies have been born, until they are discharged from maternity care.

Women who join the cohort and subsequently move out of the area before the birth of their babies will remain in the cohort.

Efforts will be made to ensure that all recruited women and their babies are followed up outside the site area in these instances.

Women who experience adverse pregnancy outcomes such as miscarriage, stillbirth, or neonatal death before consenting to join the cohort become ineligible and are not approached to join. Participants who experience adverse pregnancy outcomes following consent will remain enrolled unless they contact the BaBi study team to withdraw.

Participants under the age of 16 years are eligible. If deemed Gillick competent¹⁴, they can provide self-consent. If not, consent is sought from a parent or guardian, and the participant is approached again to consent (or withdraw) after their 16th birthday.

Training and staff engagement

All healthcare practitioners approaching and recruiting participants to the study receive training from members of the BaBi study team or directly through e-learning modules designed for the study and freely available through the National Institute for Health and Care Research (NIHR) Learn platform. Training was co-developed with midwives to ensure relevance, understanding, and feasibility. Training focuses on informed consent and follows the principles of NIHR [Good Clinical Practice](#). Additional staff engagement is achieved through regular newsletters, emails, and updates at relevant NHS Trust meetings and forums.

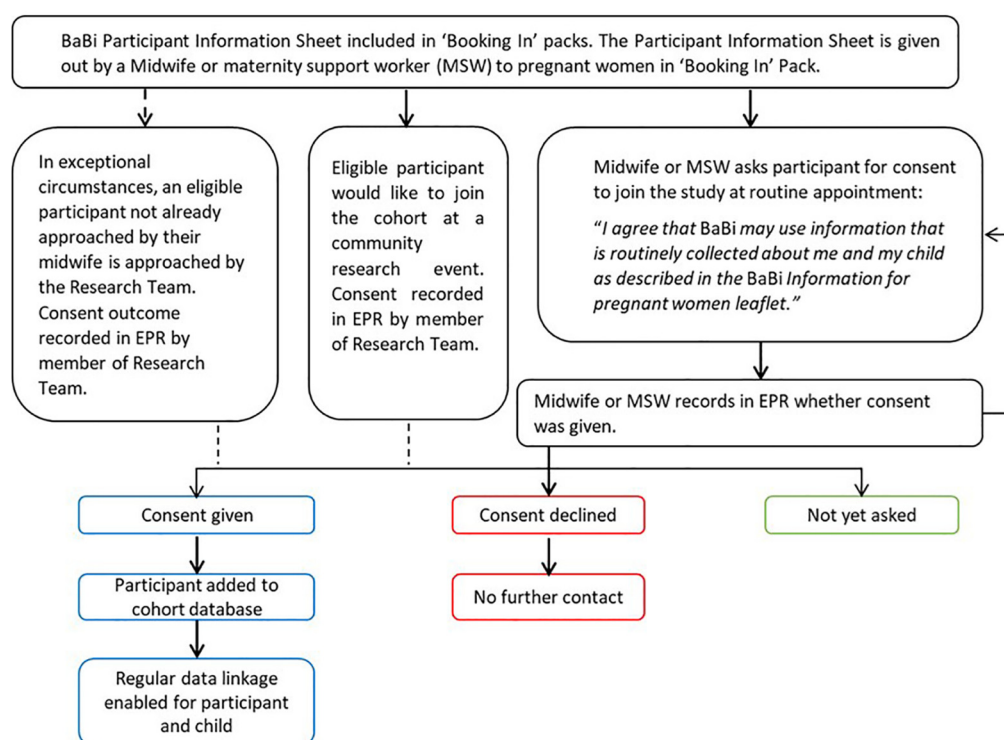


Figure 1. Flow diagram of the BaBi recruitment process.

Consent process

The consent process is embedded in routine antenatal care, delivered by trained health care practitioners (predominantly midwives), and documented in the electronic patient record (EPR). Informed consent for the study is obtained verbally from women for themselves and on behalf of their baby. Their consent is recorded digitally in the EPR in a specific consent question designed for the study. Verbal consent was chosen over written consent to align with clinical practice, where consent for many decisions is provided verbally to health care professionals and recorded digitally by them in the EPR. This method of consent was co-produced with women and midwives to ensure that the process was acceptable, ethical, informed and efficient. Consent can occur at any point during or just after birth up to the point of discharge from maternity services. In addition to consenting to access and link routinely collected data, potential participants are asked to consent to be contacted in the future for opportunities to participate in additional research.

The majority of women are introduced to the cohort and provided with information during their pregnancy booking appointment with their midwives (approximately 8–10 weeks of gestation). In some cases, maternity support workers who see women for separate antenatal appointments before the booking visit may also consent. The EPR system is programmed to remind practitioners to seek consent during encounters throughout maternity care, as shown in Figure 1. This provides a flexible and inclusive process for both women and practitioners.

Beyond routine clinical encounters, cohorts are promoted using posters and participant information leaflets, which are available in relevant areas, such as GP surgeries, community midwife clinics, Children's Centres, religious settings, and maternity units. Regular community events are also held by sites to raise the profile of the cohort and reach a wider community.

Translation

Translated materials have been made available in the ten most common community languages across the BaBi network to enable women to access information in an appropriate format.

Where languages either do not have a written form or very few people read the written form, audio recordings and video summaries of the materials are available. All translated, audio, and video versions are freely available on the central and local BaBi websites. Hard copies are available from the local BaBi research team for those who do not have access to the Internet.

Women with language needs are offered interpreting services as standard care throughout their pregnancies. Therefore, women who need this support should have an interpreter with them during routine appointments who will be able to ask questions about taking part on behalf of the healthcare practitioner.

Routine data sources

A broad range of routine data on mothers and children are included as part of the recruitment process. These include (but are not limited to) data from health records, education, welfare, and social care sources. Figure 2 shows a diagram of examples of the data sources included in the participant information leaflet.

Data management and use

Data sharing agreements are established with the relevant data custodians for each data source of interest at each participating site. Data sharing agreements detail the method of secure transfer of data and the frequency of data updates to be shared. Each agreement is bespoke to the needs of each data source. The common principles of the method are as follows.

- A list of consented participants' study ID numbers will be combined with personal identifiers such as name, address, date of birth, and/or NHS number for each participating site. This enables data linkage and record matching. This list of identifiers for consented participants will be shared with the data provider via the secure transfer method previously agreed upon between the data provider and each participating site (as specified in the data sharing agreement).
- A new version of this list will be created at the time of each linkage attempt to ensure that any participant who has withdrawn is excluded.

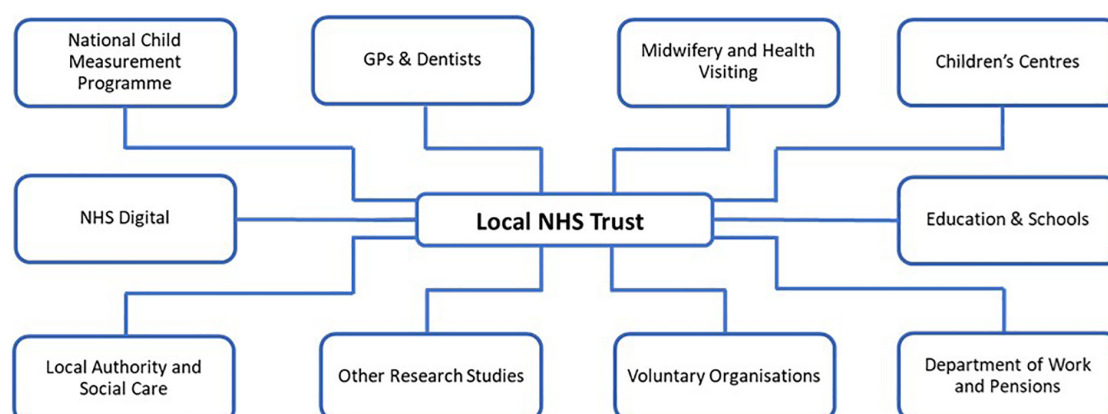


Figure 2. Routine data sources that can be linked at each BaBi site (General Practitioner shortened to GP, National Health Service shortened to NHS).

- Only the unique cohort research study ID will be retained by the data provider for future linkage. The linked data will then be sent by the data provider using the agreed secure data transfer method (stipulated within the data sharing agreement).
- Where feasible and appropriate, OpenPseudonymiser is used to create a shared pseudonymous key for data linkage and matching purposes. OpenPseudonymiser is a free to access tool created by the University of Nottingham that replaces an identifiable variable (such as the NHS number) with a non-identifiable key. It is useful in data linkage because it negates the need for identifiable data to be shared with data providers. Instead, each party uses the tool to create a shared list of non-identifiable keys for the identifiable variable, such as a look up file. This process is only feasible when each participating site and the data provider have a common identifier (e.g., NHS number) and both agree to use OpenPseudonymiser software as part of the data linkage process. This will be explored with each data provider and stated within the data-sharing agreement.

The meta-cohort

Each site is asked to contribute pseudonymised extracts of linked data to the BaBi Coordinating Centre as part of the BaBi meta-cohort. In addition to enabling national generalisability, this meta-cohort will provide larger samples with greater statistical power. At the time of writing, processes to harmonise the data have started, using principles that are agreed across sites, to develop a minimum dataset of key demographic and core metrics. Given the volume of potential data items, we are using a staged approach, beginning with the identification and harmonisation of demographic and key pregnancy outcome data available at each site, while establishing the process for a feasible common model. Over time (and with each new data request), the dataset will increase in size. Data items/outputs will be stored in a cloud based secure data environment and openly available upon request to the BaBi Coordinating Centre.

Management and governance

Each BaBi site is the data controller for the local BaBi, which means that it is responsible for the management and governance of the data collected. Each site is encouraged to establish an appropriate local partnership (or steering) group to provide oversight and support priority setting, data linkage, and use of the linked data. The data controller of the BaBi meta-cohort is the BaBi Coordinating Centre (hosted at Bradford Teaching Hospitals NHS Foundation Trust).

The BaBi Coordinating Centre manages ethical and Health Research Authority (HRA) approval, site setup, initiation, and monitoring. It is also responsible for coordinating network level data requests and expressions of interest for collaborations. In addition to these operational tasks, the Coordinating Centre support a number of 'Communities of Practice' (CoP). In these, groups of people with common roles and interests are able to share knowledge across the network, build intra-network relationships, and provide peer support. CoPs include groups for Principal Investigators (to discuss research priorities and site governance), Research Midwives (to support recruitment),

Data Operations, and Communications and Engagement. Each CoP is facilitated by a member of the Coordinating Centre team through regular online meetings. Where appropriate, team members from potential new sites are invited to join the relevant CoP to gain a more informal understanding of how sites operate.

Patient and Public Involvement and Engagement (PPIE)

Inspired by the Born in Bradford approach, co-production is at the heart of the BaBi network. The initial study design and development of documents and materials were undertaken in collaboration with community and participant groups. Involvement shaped the way consent was described, the use of example research questions in participant materials, and operational processes. A participant facing animation that complements the participant information sheet was co-produced with community members, who co-designed the content and appearance of the animation and the images and script used throughout. Members of the community are also involved in the planning for how the data are used, and the prioritisation of research questions. As research questions are answered, community members will be involved in designing the dissemination plans to ensure that findings, recommendations, and impacts are effectively shared. Each BaBi site is encouraged and supported by the BaBi Coordinating Centre to establish or access local PPIE groups to facilitate PPIE and coproduction at the site level.

Ethical approval

The protocol for BaBi was given favourable opinion by the Bradford Leeds NHS Research Ethics Committee (reference: 17/YH/0202, 3rd August 2017) and the Health Research Authority (reference: IRAS 226266, 4th August 2017). Research governance approval and Sponsorship was provided by Bradford Teaching Hospitals NHS Foundation Trust (reference: BTHfT 2173, 27th November 2018).

Early site initiation and recruitment findings

Since the launch of the first site in Bradford in 2019, the BaBi network now has 13 active sites. Table 1 provides summary information about the sites, including when recruitment commenced, the number of births per year, and the number of women and babies recruited as of January 2025.

Recruitment targets for BaBi sites start at 10% of the local maternity population at year 1 of launch, working towards 60% in year 5. At the time of writing, more than 62,000 participants have been recruited, with approximately 1500 new (maternal) participants recruited across the network each month. Based on current recruitment rates, it is estimated that by 2028, there will be more than 30,000 participants in the cohort at the first BaBi site (Bradford) alone, and between 6000 and 12,000 participants at each of the other sites, depending on when recruitment started. We have trained over 1,500 clinical staff members to obtain informed consent for the cohort from the women they care for across the network. This has increased research capacity across all sites and, in some cases, has enabled the introduction of research midwife roles at sites for the first time.

Sites are asked to capture any impact achieved onto a central document, which is an adapted version of the VICTOR tool¹⁵.

Discussion

The BaBi network works proactively with members of the public, health and care professionals, commissioners, and policy-makers to inform processes and guide priority areas. This is particularly important, given the unique way in which each site promotes local ownership of the cohort, which fosters pride, confidence, ownership, and inclusive involvement.

Each site aims to use the connected data as a local health intelligence tool to answer locally relevant research questions that can inform services. Figure 3 shows the local health intelligence model that sites use as a basis for this.

The UK government committed to using data to improve the health and care of the population in a safe and transparent way in their 2022 policy paper 'Data saves lives: reshaping health and social care with data'¹⁶. This paper sets out a strategy to achieve a health and care system that is underpinned by high

Table 1. BaBi Recruitment, by site (up to January 2025).

BaBi Site	Year of launch	Births per year (n)	Number of women recruited (n)	Number of babies recruited (n)
Bradford	2019	5,200	10,950	9,463
Doncaster	2023	3,077	1,782	1,462
East London	2023	15,000	7,356	3,663
Leeds	2023	8,000	3,729	2,735
Harrogate	2024	1,700	486	290
Hull	2024	4,500	1455	660
Northern Lincolnshire	2024	3,537	177	29
Nottingham	2024	7,798	1,077	606
Tameside	2023	2,000	599	355
Wakefield	2023	6,000	3,657	2,689
Warwick	2023	3,120	747	421
York	2024	3,200	1,183	614
Scarborough	2024	1,200	565	340

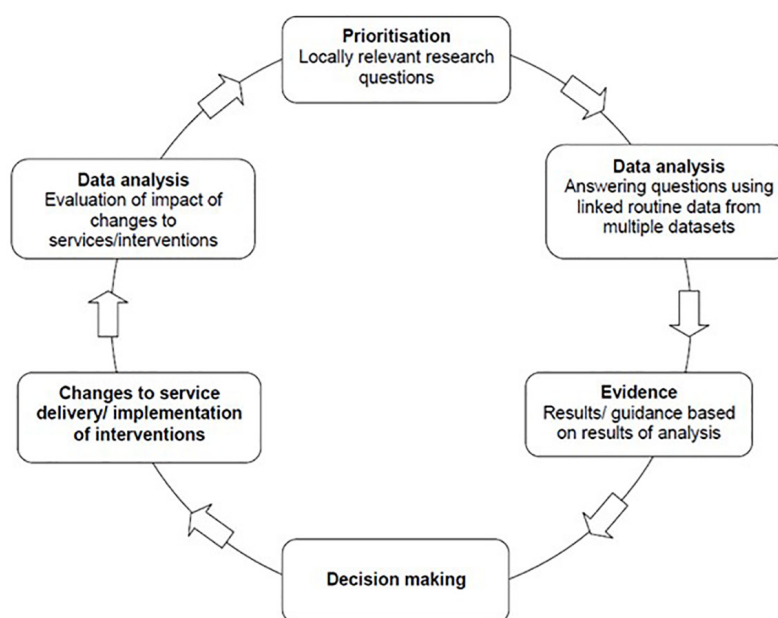


Figure 3. The BaBi local health intelligence model, describing how connected data can be used to answer locally relevant research questions and inform service delivery, implementation, and evaluation of interventions. This process involves six stages that work as a cycle.

quality and readily available data. The term ‘Learning Health System’ was first described in 2007 and has been gaining significant interest¹⁷. It describes how data from health and care systems can be used to generate new knowledge to inform how health and care services are delivered to better meet the needs of the population it serves. In 2022, a Health Foundation review highlighted a large gap between the availability and potential use of learning health systems¹⁸. Despite the increasing interest in learning health system methodology, it has not yet been translated into widespread practical applications.

The BaBi network provides a new model for harnessing the power of routinely collected data to develop insights and drive local service improvements. Embedding consent into the maternity electronic patient record at each site means that health professionals use the same system to record consent as they do to deliver care. The result is an efficient paperless design that allows for ongoing recruitment and increases the likelihood of optimal reach and inclusivity. The key principles of the BaBi model are presented in [Box 1](#).

Box 1.

Local ownership: The place-based nature and devolved model of the cohorts promotes pride and involvement from participants, practitioners, and policymakers. This is not an anonymous, central dataset but rather an engine to answer locally important questions to implement and evaluate local interventions and services and develop a learning health system ([Figure 3](#)).

Consent to link high quality data from multiple sources:

The consent to link data model means that data can be linked across sources and between mother and child (including primary and secondary care, social care, and education), providing richness and depth for analysis.

Consent for contact: Allows active engagement with families and builds a long-term, sustainable, applied research platform that can be used flexibly locally and combined for national studies.

Multi-sectoral and multi-disciplinary collaborations: Each BaBi site is a partnership of local services, including NHS Trusts, primary care, and Local Authorities.

Open and transparent public engagement: Opt-in consent promotes a benchmark of public involvement in data linkage that is open, transparent, and aims to build trust in data sharing.

Longitudinal platform, embedded in practice: Provides a strong bridge between research, policy, and practice, and strengthens capacity within each area through its ability to combine identifiable, longitudinal data that can track people over a life course, with a universal consent process that is built into routine maternity care.

Community of research and practice: The BaBi network facilitates communities of practice across different research elements (research delivery, data operations, communications and engagement, principal investigators), fostering collaboration and shared learning opportunities.

Federated data sets: cross-site working and linking/ exploration of data from multiple areas and sectors to answer nationally important questions. Large-scale datasets allow for interrogation of a diverse range of population characteristics.

Inclusive and accessible: The model provides opportunities for all women to participate with no restrictive eligibility criteria. This promotes participation from a wide range of diverse and underserved populations without restrictions owing to language, literacy, or cultural barriers. The minimal participant burden, coupled with the embedded consent approach through antenatal services, aims to ensure less systematic bias in representativeness than that seen in more traditional cohort methods.

Research awareness and capacity building: By embedding the research process into routine care, hundreds of midwives have been trained, increasing their capacity to conduct research in maternity settings. Promoting research as part of clinical practice builds awareness within the health and care workforce. Ensuring engagement with health and care professionals across all stages of the learning health system generates interest and investment in local research, and how it can be used to drive improvements.

The risks and limitations of the BaBi approach are summarised in [Box 2](#).

Box 2.

Data Quality: Routine data has challenges with consistency, missingness, and duplication^{8,19}. Routine data are also usually collected for administrative purposes, such as delivering healthcare, meaning that research-relevant outcomes may not be captured in a useful format.

Coverage and participation: Using an opt-in consent based approach is challenging and could result in cohorts that do not reflect the target population across the characteristics of interest. Monitoring participation across and within sites is important to minimise bias and ensure that recruitment processes are inclusive.

Data harmonisation: Systems and data variables are individual to each BaBi site, which poses questions as to how best to approach the harmonisation of variables for the meta-cohort. While some data of interest are available nationally, these national level harmonised datasets (e.g., Maternity Services Dataset, Hospital Episodes Statistics) often provide less granularity than local data sources and significantly fewer variables.

Impact: Driving changes and improvements of measurable impact locally and nationally through a learning health system model is reliant upon local site delivery, capacity, and commitment.

Despite the risks and limitations, the BaBi approach offers promise and potential solutions to some of these limitations. For example, having a cohort embedded in routine care offers the opportunity to drive improvements in the quality of local routine data collection, particularly where these improvements will facilitate the exploration of locally prioritised research questions.

Implications for practice

Despite its infancy, the BaBi network has already had a demonstrable impact. Examples include partnerships with NIHR Biomedical Research Centres^{7,20}, recruitment for research studies through the consent to contact approach^{19,21} and additional funded research. Sites have invested time in co-designing priority areas with key stakeholders, and our communities of practice approach across sites demonstrates the benefits

of local collaboration across sectors and services, promoting best practice, and reducing duplication of effort. There is also clear evidence of research capacity building across the network, where a number of sites had limited experience in maternity based research and adopting BaBi has led to increased involvement in other research studies.

The BaBi network is an evolving cohort that aims to take a quality improvement based approach to delivery, reflecting on its practice and refining its methods. Future planned developments for the network include (1) building a public consent management portal to allow participants to manage their consent online and to see how their data have been used; (2) exploring extending the recruitment window beyond maternity and into other routine appointments (e.g., health visits), and the extension of consent to include routinely collected biological samples as well as routine data; and (3) reviewing the characteristics of the sample and taking a continuous approach to our protocol to maximise inclusivity.

In conclusion, the BaBi network is building an efficient and inclusive birth cohort research platform that engages participants and professionals, and has the potential to harness linked data to improve health and care outcomes.

Data availability statement

No data is associated with this article. In line with the commitment of the Born in Bradford research programme, we are committed to making data available to the research community. Data from the BaBi network can be requested through the BaBi network Coordinating Centre <https://www.babinetwork.co.uk/working-with-us>. All requests will be reviewed by the BaBi Coordinating Centre leadership team every two months. A cost recovery model is used to determine the time required to generate the requested data.

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References

- MRC: Maximising the value of UK population cohorts: MRC strategic review of the largest UK population cohort studies. MRC: London, 2014.
[Reference Source](#)
- Hemingway H, Lyons R, Li Q, *et al.*: A national initiative in data science for health: an evaluation of the UK Farr Institute. *Int J Popul Data Sci.* 2020; 5(1): 1128.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- UKRI: UK health informatics research network. 2024; [cited May 7, 2024].
[Reference Source](#)
- Boyd A, Golding J, Macleod J, *et al.*: Cohort Profile: the 'children of the 90s'—the index offspring of the Avon Longitudinal Study of Parents and Children. *Int J Epidemiol.* 2013; 42(1): 111–27.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Raynor P, Born in Bradford Collaborative Group: Born in Bradford, a cohort study of babies born in Bradford, and their parents: protocol for the recruitment phase. *BMC Public Health.* 2008; 8(1): 327.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Tingay KS, Bandyopadhyay A, Griffiths L, *et al.*: Record linkage to enhance consented cohort and routinely collected health data from a UK birth cohort. *Int J Popul Data Sci.* 2019; 4(1): 579.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Carson LE, Azmi B, Jewell A, *et al.*: Cohort profile: the eLIXIR Partnership—a maternity–child data linkage for life course research in South London, UK. *BMJ Open.* 2020; 10(10): e039583.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Goldacre B, Morely J: Better, broader, safer: using health data for research and analysis. A review commissioned by the Secretary of State for Health and Social Care. Department of Health and Social Care, 2022; [cited 2024 May 7].
[Reference Source](#)
- Limb M: Controversial database of medical records is scrapped over security concerns. *BMJ.* 2016; 354: i3804.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Kerasidou A, Kerasidou CX: Data-driven research and healthcare: public trust, data governance and the NHS. *BMC Med Ethics.* 2023; 24(1): 51.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Sohal K, Mason D, Birkinshaw J, *et al.*: Connected Bradford: a whole system data linkage accelerator [version 2; peer review: 2 approved]. *Wellcome Open Res.* 2022; 7: 26.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Wright J, Small N, Raynor P, *et al.*: Cohort Profile: the Born in Bradford multi-ethnic family cohort study. *Int J Epidemiol.* 2013; 42(4): 978–91.
[PubMed Abstract](#) | [Publisher Full Text](#)
- City of Bradford Metropolitan District Council: A profile of Bradford District. 2023; [cited May 7, 2024].
[Reference Source](#)
- Griffith R: What is Gillick competence? *Hum Vaccin Immunother.* 2016; 12(1): 244–247.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Cooke J, Jones N, Holliday J: VICTOR (making Visible the Impact Of Research) Pack. Resource for a healthcare organization. Sheffield Teaching Hospital. UK, 2019.
[Reference Source](#)
- Department of Health and Social Care: Data saves lives: reshaping health and social care with data. In: Department of Health and Social Care. editor. London, 2022.
[Reference Source](#)
- Institute of Medicine Roundtable on Evidence-Based, Olsen L, Aisner D, *et al.*: The learning healthcare system: workshop summary. Washington (DC): National Academies Press, 2007.
[PubMed Abstract](#) | [Publisher Full Text](#)
- Hardie T, Horton T, Thornton N, *et al.*: Developing learning health systems in the UK: priorities for action. 2022.
[Reference Source](#)
- Dickerson J, Kelly B, Lockyer B, *et al.*: Experiences of lockdown during the COVID-19 pandemic: descriptive findings from a survey of families in the Born in Bradford study [version 2; peer review: 2 approved]. *Wellcome Open Res.* 2020; 5: 228.
[PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Genomics England: Changing the future of genetic health, together. 2024; [cited May 7, 2024].
[Reference Source](#)
- Drysdale SB, Cathie K, Flamein F, *et al.*: Nirsevimab for prevention of hospitalizations due to RSV in infants. *N Engl J Med.* 2023; 389(26): 2425–35.
[PubMed Abstract](#) | [Publisher Full Text](#)