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Supporting Local Early Years Decision-Makers in England to use Linked Data Research: A Qualitative Study

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Abstract

Introduction

Integrated Care Systems (ICSs) in England have placed a greater focus on joined up working and using data to inform local health and care decision-making. In addition, a series of birth cohorts are being set up across England, known as the Born and Bred in (BaBi) Network, which link routinely collected data across public services for consenting mothers and their babies for research and to inform local decision-making. However, there is a limited understanding of how local decision-makers can be supported to use local routinely collected data in their decision-making processes.

Objectives

This study aimed to understand how local early years decision-makers can be engaged and supported to use linked data research outputs, with a focus on using BaBi data.

Methods

We conducted qualitative interviews with fifteen early years decision-makers working in four local areas that have a BaBi cohort (Bradford, Leeds, Doncaster, and Wakefield). Participants represented a range of professional backgrounds, including local government, primary care, midwifery, health visiting and perinatal mental health services.

Results

Participants were positive about using linked data to support their decision-making but were clear there were data quality issues to overcome. Decision-maker's ability to use linked data research as evidence was hindered by their time available to engage with research, their understanding of routine data and budgetary constraints. Hence, participants described the need for accessible and convenient mechanisms to effectively engage decision-makers in research using linked data. Finally, participant's views towards their responsibility for research may be influencing their willingness to engage with and use research evidence.

Conclusions

There are important areas to further explore including the overall research culture and perceived responsibility for research across local policy and decision-making sectors. Recommendations from this research can inform how researchers work with local decision-makers to use locally linked data to support local needs.

Keywords

Child health, Maternal health, Linked data, Routine data, Decision-making, Qualitative, BaBi Network, Born in Bradford

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Introduction

The introduction of Integrated Care Systems (ICSs) in England marked a shift toward partnership working and shared responsibility, by bringing together National Health Service (NHS) organisations, Local Authorities, Voluntary Sector Organisations and others to deliver health and social care across specified geographical areas [1, 2]. The main purpose of establishing ICSs was to improve population health and mitigate inequalities. Partnership working across the health and social care sector supports this by allowing a mutual understanding of local needs and the use of collective resources to meet those needs [3]. As a result, government policy requires ICSs to use data from across the health and care system to inform their decision-making [4, 5]. This aligns with the concept of a 'learning health system', which describes how data from across the health and care system can be used to generate new knowledge, to directly improve service delivery [6].

Effective use of health service data is recognised as critical to responding to the current challenges facing the NHS [7]. However, as the wider determinants of health extend beyond clinical settings, there has also been a drive to link health records with non-health sources (such as education data) to achieve a holistic view of individual and population health [8]. Integrating these broader concepts of health into health planning requires a 'systems thinking' approach, where local decision-makers move away from viewing public services in isolation and instead, consider health as part of a complex, interconnected web of services, where changes in sectors like education or social care can also influence health outcomes and health inequalities [9]. As such, several population level datasets have been established to facilitate this (e.g. Whole Systems Integrated Dataset, Lambeth Datanet, Connected Bradford, the Discover Dataset) [8, 10–12] and there have been significant investments in linking data across services to support children and families [13, 14]. This includes the Born and Bred in (BaBi) Network; a collection of local birth cohorts across England [15]. In contrast to traditional population-based research that relies on national 'opt-out' models to use and link routine records, BaBi cohorts utilise a consent-based approach, where pregnant women are invited to join a local BaBi cohort by a trained midwife during a routine antenatal appointment. This enables recruitment to be ongoing and permits the linkage of their and their child's routine health, education and social care records for research purposes. In this paper, we use the term 'routine data' to refer to data that are collected by public services as part of their service delivery or clinical practice and research that uses data from more than one source as 'linked data research'. Each BaBi cohort aims to harness the power of routine data about local families for research to support local decision-making [15]. Local evidence can provide important insights for local decision-makers, including whether local services are working, how they are working and who for [15].

While this opt-in model means the BaBi cohorts are not strictly population-based, it represents a deliberate response to England's complex and highly contested history regarding health data sharing. Previous research with members of the public in the United Kingdom (UK) has highlighted that trust and transparent use of data for research is crucial for public

acceptance [5, 16, 17] and the BaBi consent model prioritises building this trust. BaBi participants also consent to being contacted about future research opportunities, which therefore enables the creation of a sustainable research platform that promotes inclusivity in research and transparent use of service-user data [15].

The BaBi Network was founded on the success of the Born in Bradford research cohort, which successfully linked primary research data to routinely collected data to inform local policy and practice [18, 19]. While the original Born in Bradford cohort has established a proven track record of influencing local service delivery, the BaBi cohorts were created with the aim of scaling this potential. They provide a cohort for every generation, through continuous, ongoing recruitment, which can capture a real-time picture of families experiencing policy changes to support policy evaluations and changes to service provision. The BaBi Network began with five pilot sites (Bradford, Doncaster, East London, Leeds and Wakefield) and following the success of these cohorts, has expanded to include 13 active sites at the time this paper was written, representing approximately 10% of the pregnant population in England. An up-to-date list of local areas with BaBi cohorts can be found at: <https://www.babinetwork.co.uk/babi-sites>.

Despite increased investment in linking routine data and making this accessible for research, there is limited evidence regarding how local decision-makers perceive and utilise such research. Existing studies have explored stakeholder views on population-level data sharing without explicit consent, under the lawful basis of 'task in the public interest' [20, 21], however, the utility and current use of locally owned, consented, longitudinal routine data remains under-researched.

While the challenges of using routine data for research are well documented [7, 21, 22], there is evidence to suggest these data can still be useful for informing policy decisions, particularly around child and maternal health. For example, project data have been linked with routine health and education records to evaluate the Flying Start childcare programme in Wales [23]. In England, routine health, education and social care data were linked to evaluate the Family Nurse Partnership, which provides support to young mothers from pregnancy until their child is aged between one and two years [24]. Given this potential, and because the overarching aim of BaBi cohorts is to link wide-ranging data to inform policy and practice, understanding decision-makers' attitudes around using linked routine data for research is essential, if linked data research outputs are to be used effectively to address key challenges facing the health and care system. This aligns with the core principles of implementation science, which focuses on the methods and strategies used to systematically promote the uptake of research evidence into routine, real-world practice [25]. As highlighted in this field, establishing the effectiveness of an innovation does not guarantee it can be used in practice and from this perspective, simply creating and linking datasets does not mean that decision-makers will use these datasets as evidence. Therefore, it is important to understand the human and organisational factors that can influence use of these data. This provides the rationale for the current study, as understanding these perspectives is a necessary first step toward realising the network's goal of informing local practice.

Hence, this study explored the perspectives of local clinical decision-makers and commissioners, through qualitative semi-structured interviews, regarding:

- 1) The utility of linked routine data from consented maternal and child cohorts for research
- 2) The application of such research as evidence for policy and service development around child and maternal health
- 3) Strategies for stakeholder engagement in the linked data research process
- 4) The barriers and facilitators to using linked routine data as evidence in decision-making related to child and maternal health.

This paper is based on work originally presented in the lead author's doctoral thesis focused on how research using linked routine data could support local decision-making [26].

Methods

To ensure comprehensive reporting of methods, this section is structured according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [27]. The study protocol was published prior to data collection [28].

Research Team

The qualitative interviews described in this paper were conducted and analysed by a female student (HH) as part of her doctoral research. She approached this research with an understanding of the theories surrounding the use of research evidence in decision-making and the associated barriers and facilitators [29–33]. Further details about the interviewer's prior knowledge are outlined in the published protocol [28].

A researcher may be considered an 'insider' if they share a characteristic, role, or lived experience with the study participants [34]. The interviewer was known to several of the study participants through her collaboration with the BaBi Network on other aspects of her doctoral research and could be considered an 'insider'. This offered both opportunities and challenges. For example, her 'insider status' allowed for a good rapport to be developed with participants, although there were some instances where participants drew on shared 'insider' knowledge, which required the interviewer to follow-up and ask for clarification. She remained critically aware of this and challenged her own assumptions whilst collecting, analysing, and presenting the results.

Study Design

Perinatal and early years decision-makers from four BaBi pilot sites (Bradford, Doncaster, Leeds, and Wakefield) were invited to participate in an online semi-structured interview. A critical realist approach was adopted throughout this research, meaning reality is believed to exist independently of those who observe it, and an understanding of this reality is only

accessible through individuals' perceptions [28, 35]. This approach also recognises that a person's social context can influence how they give meaning to their experiences.

Interviews were conducted online, leveraging the widespread professional adoption of digital communication tools necessitated by the Covid-19 pandemic. Participants could also take part via telephone if preferred or if there were technical difficulties.

Participant Selection

This study sought to include a diverse range of local perinatal and early years decision-makers who have the potential to utilise cross-sector linked datasets. This includes clinical decision-makers who have the potential to benefit from linking fragmented data across different health and care services (e.g., midwifery, primary care, health visiting, and early years voluntary sector organisations), as well as local council stakeholders who may require data integrated across health, education, and social care to inform decisions about early years services. A focus on local decision-makers was prioritised because the primary objective of each BaBi cohort is to act as a "local health intelligence tool" [15]. To effectively shape early years policy and practice, local decision-makers often require context-specific evidence that directly reflects the unique needs of their distinct regional populations. Hence, inclusion criteria for the study were:

- Individuals with experience in making decisions that shape the provision of maternity and early years services at the local-level, as well as those overseeing the strategic use of a BaBi cohort. Example roles included: Director of Midwifery, Public Health Consultants, Service Commissioners Project Lead of a BaBi cohort.
- Individuals working in Bradford, Doncaster, Leeds, or Wakefield, where a BaBi cohort was being established.
- Individuals with sufficient English language proficiency, enabling them to understand the study information, provide informed consent, and take part in the interview.

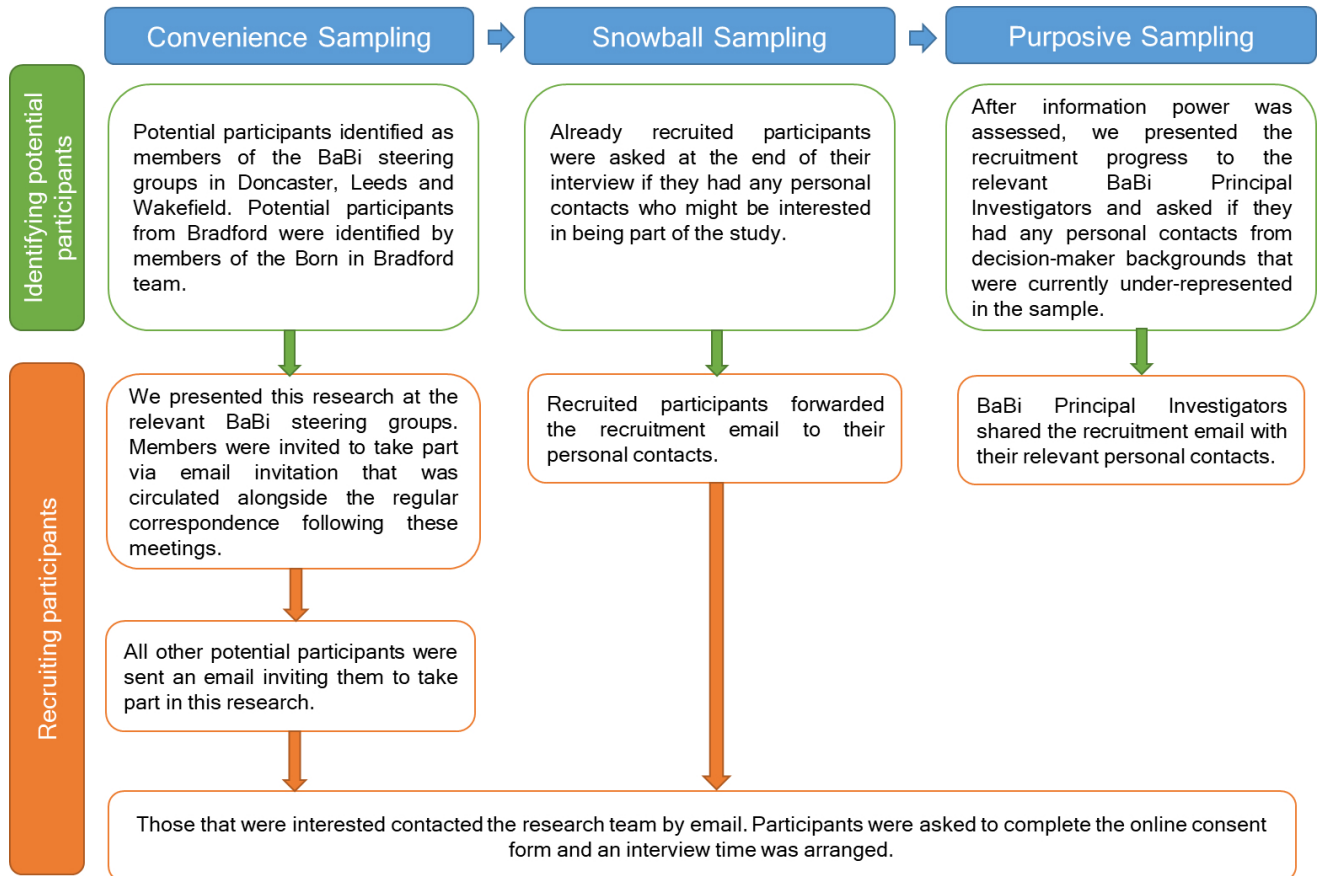
We aimed to recruit three or four individuals from each of the local areas and at least one representative from midwifery, health visiting, primary care, and commissioning backgrounds across the recruitment areas. Applying this pragmatic approach helped to achieve diversity across the relevant characteristics, without the need to recruit every type of decision-maker from each local area [26].

A range of approaches were utilised to identify and recruit potential participants. Figure 1 summarises these approaches.

In the first instance, individuals were recruited using convenience sampling of senior perinatal and early years decision-makers who were members of relevant BaBi steering groups [36]. They were invited to take part via an email invitation (see Supplementary Appendix 1) circulated alongside the regular correspondence for their meetings.

A snowball sampling approach was also used, where interviewed participants and BaBi steering group members were invited to share the study invitation with their personal networks [36]. The aim was to ensure the sample was not limited to only those closely involved in the BaBi Network.

Figure 1: Summary of Sampling and Recruitment Process



To determine whether an adequate sample size was reached, information power was assessed by the research team. Information power is an alternative to data saturation and suggests that if the sample holds highly relevant and rich data, a lower number of participants are required. It considers five elements (a) the aim of the study, (b) the sample specificity, (c) the use of established theory, (d) the quality of the discussion, and (e) the analysis strategy [37].

Finally, a purposive sampling approach was taken to recruit under-represented decision-maker backgrounds [36]. The lead researcher (HH) presented the recruitment progress to the Principal Investigators of the BaBi pilot sites in August 2022 and asked if they could share the study invitation with contacts from unrepresented professional backgrounds. Following this, information power was then reassessed, and the research team were satisfied that a diverse range of decision-maker perspectives from each local area was adequately captured.

All potential participants were provided with the participant information sheet; a supplementary information sheet detailing the study's context (see Supplementary Appendix 2); and invited to ask any questions about the study. To minimise participant burden, review of the supplementary material was optional prior to the interview; however, key contextual details were reiterated at the start of each interview.

Once the participant had confirmed they would still like to take part, informed e-consent was obtained, adhering to relevant guidance [38].

Data Collection and Analysis

Interviews were conducted between July and October 2022, during the Covid-19 pandemic. They lasted between 15 and 60 minutes, with a mean interview time of 38 minutes [26]. Interviews were recorded using the online platform, Zoom, and/or on a Dictaphone with the participant's permission and only the interviewer and participant were present during the interview.

A topic guide was followed during each interview to ensure key issues were explored (see Supplementary Appendix 3). Participants were presented with an example of a research question that was prioritised and co-produced with local stakeholders and addressed using linked routine data from a BaBi cohort, with the aim of eliciting detailed feedback on the usability of linked data outputs [26].

Interview audio recordings were transcribed intelligently verbatim, facilitated by Otter.ai [39], checked for accuracy against the recordings and pseudonymised by HH. HH also kept a reflexive diary, noting down initial thoughts following each interview. This was used during the analysis process to support theme development.

Interview data were analysed inductively according to the six-stage thematic analysis approach, outlined by Braun and Clarke, using NVivo 12.1 software [40, 41]. HH familiarised herself with the transcripts and applied a complete coding approach to enable the analysis to be data-driven [41]. To develop candidate themes, codes were organised into meaningful groups related to the research objectives. A

second researcher (SB) independently read the pseudonymised transcripts to develop candidate themes; these were then discussed with HH and any disagreements were resolved. Finally, themes were revised and named through discussion with the wider research team [26].

To enhance the credibility and dependability of the findings, a member-checking process was integrated into the study design [42]. All participants were invited to give feedback on the report before the analysis was finalised. While three participants provided feedback on the draft report, no substantive changes to the final analysis were required, confirming the resonance of the themes with the participants' lived experiences.

Reporting

A selection of quotations have been reported to illustrate key findings. To protect anonymity, all participants were assigned a participant ID and individual characteristics have not been provided, only a description of the types of decisions that they make [26].

Results

Interviews were conducted with fifteen local early years decision-makers. The sample comprised individuals from clinical (n=8), commissioning (n=5) and BaBi network (n=2) roles, distributed across four areas: Bradford (n=4), Doncaster(n=4), Leeds(n=4), and Wakefield (n=3). Participants represented local government, primary care, midwifery, health visiting and local perinatal and early life health services. Table 1 describes the participants' decision-making responsibilities [26].

Due to the implementation of the ICSs, decision-makers often covered multiple local areas. Many participants had cross-cutting roles within their organisations and had experience making decisions in several areas of early life health. The resulting depth and breadth of these data provided high information power, which facilitated a comprehensive address of the research aims with a more concentrated sample size.

Fourteen interviews were held online, and one interview was held over the phone due to connectivity issues.

Thematic Analysis

Analysis of interview data indicated four main themes: 1) value of linked data for decision-making; 2) organisational resources; 3) mechanisms for effective engagement and 4) responsibility for research [26].

Value of Linked Data for Decision-Making

This theme brings together participant's perceptions regarding the value of linked data for research and decision-making. It captures the interplay between the opportunities afforded by the BaBi Network and the constraints inherent in routine data systems.

Participants perceived value in the BaBi network's capacity to link routine data for research, emphasising its potential to provide "better insights" (I10) into the wider determinants

of health through longitudinal analysis. One respondent illustrated this through the lens of breastfeeding and child oral health:

"we think that encouraging breastfeeding is going to make a difference to a child's oral health... However, the way that data is currently captured, ... you could understand outcomes related to breastfeeding, but you couldn't then connect that to any wider determinants of health, ... and I think that potentially some of this [BaBi linked data] will allow us to have better insights into that" (I10).

When presented with a specific example of research being conducted with linked data, participants considered this research as "fundamental" and "vitally important" in ensuring their service "exists" as it "stops us having to argue that we need this money to offer this service to prevent problems arising in the future, because it would prove that there are already problems right now" (O14). It can also help commissioners "to think about how would we want to target [specific funding] and what sort of interventions would we want to deliver" to ensure that money is spent "in the right way to create better long-term outcomes and reduce health inequalities" (I10).

Beyond the data itself, the linkage process was described as a catalyst for "encouraging partnership work" between local services, as "when you're expecting partners [data] and not just your own data to inform you ... I think it helps everyone see that whatever it is you're commissioning has got a benefit for lots of different reasons" (I15). By integrating datasets across services, participants suggested that organisations could "work more seamlessly across what had previously been silos" (I12), fostering the necessary "buy-in for joint commissioning type opportunities" (I15) to address early life health issues.

However, participants maintained a pragmatic view of the data limitations, perceiving it as "a starting point" or "a flag" (I07) to prompt further research or discussions rather than a definitive solution. It was suggested that routine data is "observational in nature and not interventional in nature" where decision-makers can explore "the sorts of interventions which go on typically from day to day" to identify patterns and trends, "and then return back and devise intervention studies... to see whether the observed interventions actually do have benefits, or otherwise in properly designed interventional trials" (I08). It was suggested that "although one notices interventions in an observational study, they're not randomised, and therefore, they can only be used for hypothesis generation, in terms of what interventions are going to be beneficial" (I08). Hence, "the data itself isn't the solution" (I07) and participants felt that further research would be required for decisions about the implementation of health and care interventions.

Additionally, participants indicated that "there's lots of issues in the system in terms of how data links in together, that would be very handy to iron out" (I14) if routine data are to be used for research and decision-making. What information is captured, how accurately this is recorded, and the consistency of recording information across services and datasets were the key issues highlighted by participants.

Table 1: Description of Decisions Made by Participants

Decision-maker background	Decision-making responsibilities
Clinical	- Deciding what training is delivered to clinical staff such as health visitors and midwives. - Advising on the commissioning of perinatal services and how they are delivered. - Decisions regarding service evaluations
Commissioning	Decisions regarding service provision. This included decisions related to: - The Best Start strategy - Maternal and infant mental health services - Breastfeeding support 0-19 health visiting services - Oral health - Trauma and resilience - The provision of parental education services (particularly for vulnerable families). Decisions were made collectively as part of a team and on behalf of other organisations. Senior commissioners described managing theme leads responsible for child and maternal health, as well as service leads within the council.
BaBi Network	Those who made decisions regarding local BaBi studies described their roles in: - Setting up a study team - Applying for grants and funding - Organising BaBi steering groups - Hosting workshops to identify research priorities to address with BaBi data - Training community midwives

Datasets linking routine data were described as “*limited*” as a result of poor templates and clinical codes used to record data in electronic health systems, as well as incorrect recording of the data by professionals.

“Whilst you ... could get some really good data from the coded [routine data], because the [clinical] codes are not particularly well done, you might ... only be able to get that a question was asked, rather than anything more ... there’s some [information about patients] that I know aren’t coded, so then how will you actually be able to then follow what happens next?” (I11).

The challenge of data interoperability was exemplified by the inconsistent recording of ethnicity across services:

“Just comparing our ethnicity data with [another early year’s service] ethnicity data, we’re collecting it using different kinds of [clinical] codes... it’s very difficult to do a comparison when you’re comparing apples and pears” (I11).

These issues could be the result of decision-makers not being “*involved in designing the templates that people are coding in the first place*” (I11).

To mitigate these challenges, participants recommended “*getting the people in charge of data from each system in a room*” to standardize data recording practices, as well as embedding a culture of data literacy at the “undergraduate” and “pre-reg level” (I03) for clinical professionals. This would ensure that frontline professionals understand that an electronic patient record “*means more than what it does on the day you’re looking after your patient*” (I03).

Hence, linked data are perceived as a valuable tool for decision-making although concerns regarding the quality of the data and the limitations of the systems that record this information need to be addressed.

Organisational Resources

The interviews highlighted that the decision-makers ability to make use of linked data research is often contingent upon organisational resources, with time, fiscal constraints, and research skills acting as determinants of research engagement.

Throughout the interviews, there was an apparent tension between the resources of decision-making organisations and the professional requirements of decision-maker roles, where resources were described as influencing decision makers' ability to respond to emerging research.

"obviously, we've then got to look at resources to see if we can generate a service or provide a service that meets those needs" (I09).

In contrast, one participant noted that localised evidence provides the fiscal justification for investment, arguing that it prevents the misallocation of resources.

"But then it was left to local areas to know whether they could afford it. ... But actually, if you've got your local evidence, right, affordability follows it because you're then not wasting your money" (I03).

Time was consistently characterised as a "luxury" and "precious" commodity and a significant barrier to engagement with linked data research.

"There's only so much time any of us can put [into] research, whilst also understanding that it's kind of giving us so much learning that we want to participate" (I15).

This suggests that even when the value of linked data is recognised, its utility is often compromised by the immediate pressures of operational demands.

Developing decision-makers' understanding of linked data and linked data research were frequently discussed by participants as an enabler to using linked data research. Education around linked data focused on three key areas:

"What enables [decision-makers] a) they know about it, b) they can access it and c) they can understand the... integrity of it, so they know it's robust and safe, and they can use it, it's not made up, in the best way and they understand how to use it" (I03).

Educating policymakers was considered important, as it ensures *"that part of our community who we trust, to look after our money, and to spend it... , you know, our council leaders, or our national leaders have the right evidence upon which to base those decisions"* (I08). To facilitate this, participants recommended using examples of how the data have been used in other regions to demonstrate the tangible impact of linked data on public health outcomes.

"I know when I've been to various [decision-maker meetings] to talk about BaBi ... I've used the [public health topic] examples that Born in Bradford have done... how useful that might be for our decision making ... because then it was a concrete example of a research outcome" (I13).

The interviews revealed varying degrees of capacity and capability across different sectors. While Public Health teams were perceived as being *"well versed in what kind of data is being collected"* (I15), other sectors expressed a need for further support and how they would benefit from developing

an understanding of *"the types of data that there are. Because I think you often know what's available in your own sector, you don't necessarily know what's available in other people's"* (I07). This interest in expanding routine data knowledge suggests that targeted efforts to increase data literacy would be well received by the decision-making community

Mechanisms for Effective Engagement

Participants emphasised that engagement strategies must be convenient and non-burdensome to be effective. This is because *"all the stakeholders that you want to engage, tend to be quite busy, important people who tend to be pulled in all kinds of directions and really have to kind of prioritise their time"* (I01). Therefore, research outputs need to be *"quick to engage with"* to ensure decision-makers can *"make use of all the intelligence coming up"* (I15). This requirement for brevity links to the time pressures and tension between resources and the decision-maker roles described under the previous theme.

Participants proposed bringing researchers and decision-makers together to discuss linked data research findings as an effective way to support the use of this research in decision-making. Participants suggested having *"an open workshop for any sort of stakeholders, staff, etc, within that area, so that [researchers] can present [the research]. And so, it gives you a chance to ask questions and get clarity around what it means. And how we're going to work together to then implement any actions"* (I06). Similarly, hosting *"knowledge exchange type events"* involving *"people who are actively involved in using the BaBi data... sharing what they did, what they found, how they used, how it was used in policy and practice and the opportunity for local government officers and decision makers to meet the academics and sort of get to know each other a little bit"* (I13) was suggested. These forums serve a dual purpose as they allow for the sharing of practical policy applications and provide a space for local government officers and clinical decision-makers to build rapport with academics.

The utility of direct researcher-practitioner dialogue was exemplified by one decision-makers' experience with a complex intervention study. The research project had published several research outputs, and the decision-maker wanted to utilise the research, but due to time constraints, was unable to process all the information. The participant described how being able to speak to the researchers directly about the research enabled them to make better use of the findings.

"[The researchers] have published [a number of] different research papers, one about implementation, one about feasibility, one about acceptability... But I have to read like 23 million different research papers. So, instead, what I did last week was email them to say, could we have ten minutes to just chat through exactly what all of these tell me and if you had x amount of money, what you would do? And so that's what we did..." (I15).

Participants advocated for multimodal dissemination strategies, to support decision-makers to use linked data research evidence, where each involved a short time commitment from decision-makers. For example, presenting the research in short-form content such as a *"short video or infographic"* or as *"summary type information"*, enables

decision-makers to “*really quickly link [the research] into some of the priorities and things [they are] working on*” (I10) and “*go back to the original research papers if we want to see what the actual kind of data was*” (I15). This layered approach is effective as it allows decision-makers to digest the main headlines immediately and they only need to explore the research in more detail if required by their specific decision-making context. This preference for accessible, convenient formats was consistent across clinical and commissioning roles in all geographical areas.

Responsibility for Research

When asked about how they could be engaged and supported to use research with linked routine data, participants discussed research as either part of their decision-making role or as an additional responsibility. This theme represents how the different types of decision-makers perceive their role in research and how these perceptions influence engagement with linked data research projects and research more generally. Participants’ views towards their *responsibility for research* underpins many of the discussions captured in the other themes, hence, this is considered an underpinning theme.

A prominent discourse among participants was the characterisation of research as an “*academic*” endeavour and distinct from their core responsibilities and “*practical job*”. Those who viewed research as the responsibility of academics, described struggling to find the time to engage with linked data research as they prioritise other responsibilities. This links to the theme around *organisational resources*.

“I’d love to spend all [their] days kind of reading [research]... that’s not the nature of my job, because I am not an academic” (I10)

“Most healthcare professionals couldn’t give two hoots about research. It’s, it’s such a sort of seen as so that’s an additional extra to their daily lives” (I08).

“It’s the capacity, it’s whether [decision-makers’ have] actually got the time outside, you know, given other pressures that they have” (I13).

Because research was often viewed as outside their primary scope, participants argued that the role of the research team should not be undervalued. “*because actually, [researchers have] got this kind of luxury of time and the luxury of not being embedded in a day to day thing, which is about decision making, or managing teams... so actually, [they] need [researchers] to do some of our thinking for [them]*” (I10). This implies that participants felt researchers were not only responsible for doing the research, but for suggesting how it can then be implemented. This is also apparent in the theme ‘*mechanisms for effective engagement*’, as participants describe how researchers can make their research accessible and convenient and advise decision-makers on what the research means for policy and practice.

This contrasted with the views of a subset of decision-makers who viewed research as an inherent part of their professional identity and who made time for it, often in addition to other competing priorities. Consequently, a

decision-maker’s personal and professional alignment with evidence-informed practice serves as a primary driver of how they prioritise research engagement amidst competing demands

“I feel in a really fortunate position because I have loads of time... allocated for reading and catching up on evidence that’s out there. And I know my clinical colleagues don’t have that luxury a lot of the time, and they’re really busy... But they’re still under the same obligation as I am to revalidate and to demonstrate that I know what’s happening locally, regionally and nationally, in terms of evidence” (I05).

Discussion

Analysis of interview data with local early years decision-makers has provided an understanding of their views regarding the utility of linked data research for informing local decision-making and how researchers can effectively engage and support decision-makers to make use of these data as evidence [26].

Our findings demonstrate that local decision-makers perceived value in using local linked routine data for research and to inform decision-making, viewing it as a critical “starting point” for evidence-based practice. Participants highlighted the unique evidence contribution of linked data, that separate, unlinked datasets cannot. Rather than looking at individual services in isolation, linking data across health, education, and social care allows decision-makers to gain better insights into how the wider determinants of health impact families over time. Furthermore, because this evidence is generated locally, it provides local commissioners with a powerful tool to justify funding and protect services, in contrast to research evidence generated from populations that may not match their local demographic. By proving that specific problems exist within their own populations, local decision-makers can confidently target resources to reduce health inequalities.

It was expected that participants would attribute some value to linked datasets given the recent large investments in data linkage made by local government [13, 43]. They were also either involved in a local BaBi steering group or were contacts of those involved in a BaBi steering group, meaning that many participants had heard of linked data and its potential benefits. Furthermore, local BaBi teams were working with partners across the NHS and Local Authorities to promote BaBi. The experiences of decision-makers involved in a BaBi steering group broadly resonated with those not as closely involved in BaBi.

While the appetite for linked data was high, participants highlighted that its practical application is often undermined by poor data quality. This study identified two main reasons for this: 1) inadequate electronic health record systems used to record these data, and 2) limited understanding by health and care professionals regarding how these data are used beyond clinical care. These discussions reflect the current research evidence, which suggests that the quality of routine data is limiting its potential for research and decision-making [7, 20, 44, 45]. From an implementation science perspective, accurate data entry at the frontline is itself a critical behavioural

intervention that requires targeted implementation strategies. To address these challenges, participants suggested that data literacy should be a core part of professional training, whereby health and care professionals develop an understanding of how routine data is used for research and service planning beyond the immediate clinical appointment. The eHealth Swiss initiative in Switzerland [44] offers a valuable example of how to integrate digital health topics into professional education and learning from this could be used to develop training for local policymakers and health care professionals on the importance of accurate routine data capture.

However, the benefits of improving data literacy among health professionals is limited by the current constraints of electronic record systems. Hence, to improve the quality of routine data for research, electronic record systems must be co-designed and developed to meet the needs of all end-users. This includes the needs of researchers, senior managers, national policymakers, patients or carers [7]. The NHS long-term plan has a strong emphasis on digital transformation, which provides the opportunity to improve data sources and data linkage across the health system [46].

To further support local decision-makers to utilise linked data research, participants advocated for engagement strategies that prioritise convenience and relationality. This is consistent with the wider literature suggesting that the “research-to-policy” gap is best bridged through building collaborative relationships and presenting research in easily accessible formats [29–32]. The preference for layered information, such as infographics and executive summaries, backed by full research papers, allows decision-makers to perform rapid evidence appraisals without being overwhelmed. For researchers, this implies that the dissemination phase of a project is just as critical as the analysis. The “right conversation at the right time” (I15) suggests a move toward consultative research models where researchers are available to provide brief, high-impact verbal syntheses of their findings to time-poor stakeholders. Further research is required to understand whether communicating the research outputs in the way participants have described is effective at influencing the uptake of the linked routine data research in policy or service provision.

Time and capacity constraints were frequently discussed as barriers to engagement with linked data research, a finding echoed in the wider ‘research use’ literature [32]. Our findings suggested that these constraints are driven by how decision-makers’ perceive their professional responsibilities. Specifically, while they valued linked data, many viewed research as being outside of their core remit. Consequently, research engagement may be deprioritised in favour of tasks seen as more central to their primary roles. This demonstrates that an understanding of the users’ individual and behavioural context is critical for designing effective linked data implementation strategies.

Our findings also imply that some decision-makers feel it is the researcher’s responsibility to promote their findings in a way that decision-makers can easily take action. This leaves a gap between research findings and practical solutions, and it is currently unclear who is responsible for filling that gap.

Existing evidence has suggested that policymakers often lack organisational support or training to use research effectively [33] and this could explain why some decision-makers’ do not view research as part of their responsibility.

This implies that sustainable evidence uptake cannot rely solely on individual motivation and requires implementation strategies aimed at organisational and structural shifts. Specifically, to influence how linked data research is utilised, these organisational strategies must formally embed research engagement into decision-makers’ core job descriptions. Further exploration into if and why some decision-makers perceive research as outside of their core responsibilities and if this is the reason they feel unable to give up their time to engage with linked data research is essential for designing more effective collaboration strategies.

The evolving landscape of the UK health system provides a timely opportunity to institutionalise research engagement. The transition to ICSs encouraged cross-sectoral collaboration and research is a key element of their strategies [4]. Simultaneously, the establishment of National Institute for Health and Care Research (NIHR) Health Determinants Research Collaborations (HDRCs) specifically aimed to embed a culture of evidence-based policymaking within local authorities [47]. These structural shifts represent a move toward collective accountability for research and evidence. Moreover, evidence from a project scoping research activity in Bradford Metropolitan District Council suggests that they are willing to respond to invitations to collaborate in research, are willing to share data and there is evidence of some use of research in policy developed in some departments, meaning they have the potential to benefit from BaBi data and research [48]. Consequently, as research becomes an embedded consideration within local government and health and care services, the perceived lack of time to engage with research may diminish.

Study Limitations

This study collected data on a diverse range of early years decision-makers across NHS and local authority organisations, in four local areas in the Yorkshire and Humber region. However, several contextual factors must be considered when interpreting the generalisability of these findings.

First, the sample may be biased toward those with a favourable view of linked datasets, as decision-makers with a personal or professional interest in the topic may have been more likely to take part in this research. These data were also collected during the Covid-19 pandemic, at a time when local services were under considerable pressure, which may have influenced which decision-makers were able to take part. Nevertheless, the alignment of our themes with broader literature on research evidence use suggests that these findings remain highly relevant to other BaBi Network sites and similar locally linked data initiatives.

We also acknowledge that this qualitative inquiry was about research and conducted by a researcher, which may have influenced how openly participants share their views. Participants may have been reticent in sharing their views, particularly when discussing the frustrations or barriers they face with the research community. To mitigate this, the lead interviewer made it clear that we valued all perspectives, especially those that challenged the status quo. Despite these reassurances, it is possible that participants did not feel comfortable being fully critical during the interviews.

While data collection and initial coding were performed by a single researcher, we believe that ongoing discussions

amongst the research team and member checking allowed for an analysis that remains faithful to the data.

Implications and Recommendations

To support time constrained local decision-makers to utilise linked data research, we recommend that researchers and those working with these data (such as local BaBi teams):

- a) Establish a platform that facilitates short and regular communication with relevant local decision-makers. This can enable discussions about how data and research can support local priorities.
- b) Present their research in easily accessible summaries.
- c) Collaborate with local services and companies who design data systems, to ensure electronic health record systems can capture all relevant information to enable better data for both research and health care delivery.

By collaborating with local services to improve the data systems, this may also foster a deeper understanding among practitioners of how their data can be used beyond clinical care for research. The BaBi teams have already established a strong foundation for this by embedding consent processes into routine midwifery practice and building direct partnerships with maternity data system providers. These relationships, alongside wider engagement via local steering groups, create a clear pathway for tackling the systemic issues that currently limit the utility of routine data.

As a result of this research, the BaBi Bradford team have collaborated with several local services to understand how the quality of their routine data could be improved. This included understanding how data are inputted by local services (including maternity, health visiting and specialised early life health services) and how the electronic patient record system needs to be changed to accommodate efficient data collection by services. Addressing these technical barriers is essential, as without reliable, high-quality data, the research community cannot produce the robust evidence needed to inform meaningful changes in policy and service delivery.

To bridge the gap between research and policy, England could adopt a model similar to that developed by the Manitoba Centre for Health Policy in Canada. The Centre works with a 'Need To Know' team who provide a platform for a two-way exchange between researchers and regional health planners [49]. By involving decision-makers in the formulation of research questions, building their methodological literacy and understanding of how data can be used to answer these questions, the model ensures that findings are both relevant and credible to decision-makers. Replicating this continuous communication loop in England would significantly enhance the impact and utilisation of linked routine data within local health services.

The establishment of ICSs and HDRCs have supported a more system-level approach to research, meaning the narrative around the responsibility for research is changing. As further changes are made, future research could explore whether these changes have enabled better use of routine data to inform local health and care decision-making, as there is greater support for everyone to be involved in research.

Conclusion

This study explored how local early years decision-makers perceive and utilise linked data research. As the BaBi Network represents a novel data linkage infrastructure for local authorities, understanding these perspectives is vital for ensuring that linked data research translates into meaningful local impact. Our analysis suggests that for routine data to truly influence policy and practice, a fundamental shift is required in how data systems are designed and how research responsibility is defined.

To achieve this, electronic health record systems should be co-designed to ensure they are technically capable of capturing high-quality data that meets the needs of both frontline practitioners and researchers. Furthermore, effective research engagement can be supported by structured communication channels, which facilitate a continuous, two-way exchange between researchers and decision-makers. However, these technical and communicative improvements may only succeed if the narrative around research responsibility is transformed. For engagement efforts to have a lasting impact, research use must be embedded into the core professional identity of decision-makers, rather than being viewed as an additional or peripheral task.

This research offers insights for early years data linkage studies on how to better support and engage with local decision-makers. As such, the BaBi Bradford team has already begun applying these findings to their ongoing collaboration with local services, working to refine data quality at the source.

The current rise in evidence-users within the UK and the increased investment in data linkage makes this research timely. By addressing the disconnect between researchers and policymakers through better system design and clearer professional accountability, we can move toward a landscape where routine data is effectively utilised to inform the best possible care for children and families.

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Statement of Conflicts of Interest

No conflicts of interest were declared.

Ethics Statement

Ethical approval for this study was granted by the Department of Health Sciences Research Governance Committee at the University of York on 4th February 2022 (HSRGC/2022/488/A).

Data Availability Statement

Data generated during this research project are not publicly available due to ethical and privacy restrictions. Although these data have been pseudonymised, the participants occupy senior decision-making roles, making them potentially identifiable. To maintain both the integrity of the data and participant confidentiality, access is restricted. Data are available for research purposes upon reasonable request. Interested researchers may apply for access by contacting Born in Bradford [Email: borninbradford@bthft.nhs.uk Website: <https://borninbradford.nhs.uk/our-data/how-to-access-data/>]. Use of these data are subject to the Born in Bradford Executive Committee's approval.

AI Disclosure Statement

The authors used Otter.ai for the purpose of transcribing the interview transcripts and Gemini for the purpose of language editing in this manuscript. The output was reviewed and verified by the authors.

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Abbreviations

BaBi:	Born and Bred in
COREQ:	Consolidated Criteria for Reporting Qualitative Research
HDCR:	Health Determinants Research Collaborations
ICS:	Integrated Care System
NIHR:	National Institute for Health and Care Research
NHS:	National Health Service
UK:	United Kingdom:



Supplementary Appendices

Supplementary Appendix 1: Participant Information Sheet

Supplementary Appendix 2: Supplementary Information Sheet

Supplementary Appendix 3: Interview Topic Guide



Supplementary Appendix A4: COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	5
Occupation	3	What was their occupation at the time of the study?	5
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	5
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5-7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5-7
Sample size	12	How many participants were in the study?	8
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	7
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	8-9
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the interview or focus group?	8
Duration	21	What was the duration of the interviews or focus group?	7
Data saturation	22	Was data saturation discussed?	7, 9
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	8
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	8

Continued

Supplementary Appendix A4: Continued

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	10-16
Data and findings consistent	30	Was there consistency between the data presented and the findings?	10-16
Clarity of major themes	31	Were major themes clearly presented in the findings?	10-16
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	10-16

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349–357.

