Views of parents, adults born preterm and professionals on linkage of real-world data of preterm babies

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ABSTRACT *(250/250 WORDS)*

Objective: To explore views of parents of preterm babies, adults born preterm, and professionals, on the linkage of real-world health and education data for research on improving future outcomes of babies born preterm.

Design: Three-stage mixed-methods participatory design involving focus groups, a national survey and interviews. Survey participants who expressed uncertainty or negative views were sampled purposively for invitation to interview. Mixed methods were utilised for data analysis.

Setting and participants: All data collection was online. Participants were: focus groups – 17 parents; survey – 499 parents, 44 adults born preterm (total 543); interviews – six parents, one adult born preterm, three clinicians, two teachers.

Results: Three key themes were identified: 1)Data linkage and opt-out consent make sense for improving future outcomes. We found clear demand for better information on long-term outcomes and strong support for data linkage with opt-out consent as a means of achieving this. 2)Information requirements – what, how and when. There was support for providing information in different formats and discussing linkage near to, or following discharge from, the neonatal unit, but not sooner. 3)Looking to the future; the rights of young people. We identified a desire for individuals born preterm to be consulted in the future on the use of their data.

Conclusion: With appropriate information provision, at the right time, parents, adults born preterm, and professionals are supportive of data linkage for research, including where temporary identifiers and opt-out consent are used. Resources are being co-produced to improve communication about routine data linkage.

KEY MESSAGES

What is known?

- Data on long-term outcomes are important to patients and their families, and necessary to evaluate the impact of neonatal care and intervention.
- Linkage of routinely collected datasets is a feasible and cost-efficient method to obtain long-term outcome data.

What this study adds?

- Parents of preterm born children, adults born preterm, and professionals are very supportive of data linkage with opt out consent.
- Most stakeholders are supportive based on basic written information; a minority who are not, become supportive when additional information is provided in an accessible format.

How this study might affect research, practice, or policy

- Information on the use of data should be provided at or after discharge from neonatal care, and consultation of children beyond school age, regarding linkage of their data, is a priority for further research.

BACKGROUND

Survival of the most preterm babies born before 26 weeks has improved over time, (1) but rates of disability remain unchanged. (2, 3) Cognitive impairment is the most prevalent disability and contributes to poor educational attainment. Over half of surviving extremely preterm infants require educational support; (4) 23% have mental health problems such as autism, attention deficit, and emotional disorders. (5) There is high risk of rehospitalisation and mortality in infancy (6) and of asthma. (7) In later life, there is increased risk of type 2 diabetes and cardiometabolic problems. (8) Long-term outcomes data are needed to evaluate the impact of neonatal care and interventions, (9) however, tracking long-term outcomes following hospital discharge is complex and expensive, with high attrition. As such, there is paucity of population level long-term outcomes for very preterm babies born in the UK since 2006. (10) The NIHR-funded NeoWONDER research programme will address this by linking the UK National Neonatal Research Database (NNRD) (11) to other health and education datasets to obtain information on the later status of preterm babies born in England and Wales 2007-2020. Patient and family perspectives on outcomes following preterm birth are increasingly used to inform research priorities. Mixed methods approaches have previously been used in a study on parental perspectives on health outcomes in preterm birth, to provide both breadth and depth of data (12). Patient and parent involvement (PPI) in study design beyond outcome selection is crucial in ensuing acceptability, and maximising participation. In this study, which is part of NeoWONDER, we explored the views of parents of preterm babies, adults born preterm and professionals, on the acceptability of linkage of routine data for research.

METHODS

We used a three-stage mixed-methods design involving focus groups, a national survey and interviews (Figure 1). Participants were recruited through the NeoWONDER PPI group. This group of approximately 600 parents of preterm babies and adults born preterm signed up to the NeoWONDER “Get Involved” page (www.neowonder.org.uk) launched in September 2020. All data collection was conducted online due to the COVID-19 pandemic. (13) The principles of participatory research (14) and the Consolidated Criteria for Reporting Qualitative research (COREQ) guided our work. (15)

Focus groups and co-designed national survey

The aim of the focus groups was to co-design a national survey to seek the views of parents and adults born preterm on linking routine health and education records with neonatal records. Focus group participants were recruited through an online advert circulated to the 600 members of the PPI group (Fig 1). Prior to the focus group meeting, they were provided with a draft version of the survey. CB (clinician), MS (qualitative researcher), and a preterm-born peer researcher facilitated three one-hour focus groups involving 17 participants. The groups discussed survey content, format and dissemination, and ways to ensure inclusion of harder-to-reach groups. Only one participant who signed up to the focus group did not attend.

These discussions strongly influenced the survey design. In particular, questions capturing demographic data were perceived as intrusive so were minimised.

The final online survey (Supplementary S1) was constructed using the Imperial College Qualtrics platform and piloted with three parent collaborators before being advertised on social media, and via posters in 15 neonatal units. Survey responses were de-identified prior to analysis using Microsoft Excel.

Semi-structured interviews

The aim of interviews with parents and an adult born preterm was to enable more in-depth understanding of issues of interest in the survey data. We identified information-rich cases from the survey where uncertainty or negative views were expressed, then sampled purposively from this subset ensuring maximum possible diversity of (self-reported) demographic criteria in the sample. (Supplementary S2) (16). Data collected so far suggested that opposition was unusual and for a narrow range of reasons. We anticipated, therefore, that 6-8 interviews would provide sufficient insights, with scope for more if data saturation was not achieved. Semi-structured interviews were conducted with diagrams offered to interviewees to explain data flow. (Supplementary S3) The interviews were conducted by CB and MS.

The aim of interviews with professionals (carried out by EvB) was to learn more about their views on data linkage. We purposively sampled for professionals who care for preterm-born children in health and education settings; some were known contacts, others recruited using snowballing techniques, were unknown (17)

Interviews were recorded and transcribed, with thematic analysis conducted manually. All three investigators participated in a systematic coding process. Survey and interview findings were triangulated to identify meta-themes across them. (18) Regular team discussions considered discrepancies within and across datasets, and agreed final themes.

Ethics and approvals

We obtained research ethics approval from the Yorkshire and The Humber-Leeds East Research Ethics Committee (Reference 20/YH/0330, IRAS ID 291612).

RESULTS

Survey and interview participants

Of a total of 543 survey respondents, the majority (87%) were mothers of preterm-born children. The current ages of preterm-born children of parent respondents ranged from ‘currently in neonatal unit’ to 32 years. Participating adults born preterm were aged 20 to 68 years. Parents frequently reported their preterm child as having ongoing health needs (41%) or educational needs (26%). Interview participants included one adult born preterm, four mothers and two fathers, all of whom expressed negative or uncertain views on aspects of data linkage in the survey (See table 1 and table S4 for survey and interview participant characteristics). None declined to be interviewed. Five professionals were interviewed: a neonatologist; a disability paediatrician; a professional with digital health expertise; two teachers. One clinician had experience as a parent to a preterm child. One neonatologist and one neonatal nurse declined due to scheduling conflicts. All interviews lasted 20 – 30 minutes. Data saturation appeared to be reached following the interviews.

Table 1: Characteristics of survey respondents

Characteristic	Category	Number N = 543	% (to one decimal place)
Relationship to preterm birth†	Mother to a child born preterm	474	87.3
	Father to a child born preterm	25	4.6
	Adult born preterm	44	8.1
Gestation (if multiple children then youngest gestation) †	<25 weeks	59	10.9
	25 – 27 + 6 weeks	138	25.4
	28 – 31 + 6 weeks	189	34.8
	32 – 36 + 6 weeks	152	28.0
	Missing	5	0.9
Ethnicity of participant†	Asian	11	2.0
	Black	9	1.7
	Chinese	1	0.2
	Mixed	7	1.3
	White	509	93.7
	Other	3	0.6
	Missing	3	0.6
Region of majority of neonatal care†	East	23	4.2
	Midlands	73	13.4
	Northern Ireland	5	0.9
	London	76	14.0
	Northeast, Yorkshire and Humber	93	17.1
	Northwest	36	6.6
	Scotland	28	5.2
	Southeast	54	9.9

	Southwest	122	22.5
	Wales	16	2.9
	Other	17	3.1
	Missing	0	0.0
Parent reports ongoing health needs‡	None	270	54.1
	Yes – a few	186	37.3
	Yes – a lot	19	3.8
	Other	14	2.8
	Blank/ prefer not to say	10	2.0
Parent reports additional educational needs‡	None	281	56.3
	Yes – a few	101	20.2
	Yes – a lot	27	5.4
	Other	78	15.6
	Blank/ prefer not to say	12	2.4
How many preterm-born children cared for by parent‡	1	350	70.1
	2	139	27.9
	3	7	1.4
	4	0	0.0
	4+	3	0.6
Current age of preterm-born child (eldest if more than one preterm-born child)‡	Currently in neonatal unit	11	2.2
	< 1 year	74	14.8
	1 – 5 years	226	45.3
	6 – 10 years	109	21.8
	11 – 15 years	45	9.0
	16 – 20 years	20	4.0
	> 20 years	14	2.8
Current age of adult born preterm (years)§	20 – 29	18	41.0
	30 - 39	19	43.2
	40 +	7	16.0

† Questions posed to all respondents: N = 543
‡ Questions posed to parents only: N = 499
§ Questions posed to adults born preterm only: N = 44

Themes

From the survey and interviews we identified three themes.

Theme 1: Data linkage and opt-out consent make sense for improving future outcomes

The overwhelming majority (>98%) of survey respondents felt better information on long-term outcomes of preterm babies to be important. This high level of support was consistent for: 1) health 2) behavioural, personal, social and emotional development 3) education (Table 2).

Table 2: Survey results: questions on importance of long-term data and until what point linkage should be carried out

Question	Response options	Number	%
How important is having better information on how preterm children develop as they grow up (i.e. their long-term outcomes)? n=543	Very important	418	80.2
	Quite important	99	19.0
	Not important	1	0.2
	Not sure	3	0.6
	No response	22	4.0
How important is information on longer term health of preterm babies n=543	Very important	456	87.5
	Quite important	60	11.5
	Not important	2	0.4
	Not sure	3	0.6
	No response	22	4.0
How important is information on behavioural, personal, social and emotional development of preterm babies? n=543	Very important	465	87.5
	Quite important	52	10.0
	Not important	1	0.2
	Not sure	3	0.6
	No response	22	4.0
How important is information on educational progress for preterm babies? n=543	Very important	432	82.9
	Quite important	79	15.2
	Not important	5	1.0
	Not sure	5	1.0
	No response	22	4.0
How closely related do you think a child's health and their learning/educational progress is? n=543	Very closely related	290	55.7
	Related	189	36.3
	Possibly related	37	7.1
	Not related	2	0.4
	Not sure	3	0.6
	No response	22	4.0
Till when do you think it is acceptable to link preterm children's data? n= 471	I don't think it is acceptable ever	7	1.5
	I agree with the principle of lifelong data linkage but would like the opportunity for my child to be consulted for their views when they are older (e.g. 16 or above)	284	60.3
	Until they have completed education	41	8.7
	Until the age of 18 years as legally they will be an adult	70	14.9
	Lifelong	56	11.9
	Other	13	2.8
	No response	72	15.3

Interview and free text survey data illustrated powerfully the challenges posed by the current lack of available information.

"The difficulty in having a preterm baby is having no gauge, comparison or reference" (survey participant - mother of five-year-old born 24 weeks)

"… probably my biggest worry now is what's going to happen in the future and it is just an unknown which makes it much worse" (interviewee - mother of one-year-old born 25 weeks)

Most survey respondents (92%) supported linkage of anonymised existing records, including 'sensitive' information such as special educational needs or free school meals (Figure 2). When asked for views on temporary use of identifiers for linkage purposes, such as child's name and postcode, 88% of adults born preterm remained supportive of linkage. However, support amongst parents fell to 74%, with the remainder either unsure and wanting more information (24%) or opposed (3%).

A majority of survey respondents were happy with data linkage for research purposes to be made routine (76%). Again, the remainder were mainly unsure, with only 2% expressing negative views. 69% were happy for the use of records without consent if they were always anonymous. (See quote 1, table 3).

Table 3: Additional quotes

Reference number	**Quote**	**Participant characteristics**
1	*"I think the opt out way is a good way of doing it because you're still [saying] 'yes', [but] people can say, "No" if they choose that they don't want their information to be used.*"	Interviewee - adult born preterm at 29 weeks
2	*"You want to know who's got their hands on that sort of data…if it's in the right hands, in professional hands, then I'm happy."*	Interviewee -father of four-year-old twins born 27 weeks

3	*“If it’s as you’re saying it [the data] is separated out and there’s not one person that can see the whole picture then that’s fine.”*	Interviewee - mother of one-year-old born 26 weeks
4	*“I think it probably needs to be done in a multitude of ways. So for some people they’re visual learners so you know a video would explain it, but other people, they might benefit from having it written down.”*	Interviewee – mother of 10-year-old born 29 weeks
5	*“Telling a story would be a better way.”*	Interviewee – father of 18-month-old twins born 26 weeks
6	*“I’d be comfortable [with linkage] definitely until they're 16. But at that point I guess then you'd need to look at whether the child, as they're going into adolescence, whether they're happy to have their information shared.”*	Interviewee- mother of seven-year-old born 25 weeks

Survey responses by parents and adults born preterm were found to be similar (except where otherwise stated), with a slightly greater proportion of supportive responses from the adult born preterm group throughout. The relatively high rates of support reflect an altruistic desire to ‘give something back’ and a commitment to helping individuals in the future.

“… if we can help to make life easier for any other parents going through the situation or to help with the care of premature babies then we’re all up for it. (Interviewee - mother of seven-year-old born 25 weeks)”

All professionals interviewed were strongly supportive of data linkage and the use of identifiers with opt out consent. One clinician felt that as data is necessary for an effective service, there is a moral argument that using data for research ‘trumps’ the rights of those who wish to use the service but have their data excluded. Another clinician argued that the study design is “*direct care, delivered retrospectively… to understand decisions already made”.*

Theme 2: Information requirements – what, how and when

Interviews demonstrated that uncertainty or negativity in the survey generally stemmed from a lack, or misunderstanding, of information. Findings regarding the ‘what’, ‘how’ and ‘when’ of information provision are presented below.

What

Our qualitative data demonstrated the following assurances were important to those uncertain about data linkage: i) only trustworthy professional organisations would handle data ii) data would only be used for legitimate research purposes iii) data would be processed using secure, split-file methods iv) only routine data that already exist, and not new collections, would be linked. (See quotes 2 and 3, table 3).

Explaining the following was also considered key to enabling parents to balance risk versus benefit: i) the potential benefits of data linkage ii) a requirement for opt in consent will likely render data linkage unfeasible, not least because of resource implications. Professionals also thought these points were key to acceptability for parents.

How

Only brief written information could be provided in the survey, while interviewees saw illustrations of data flows, including the secure split file component (Supplementary S4), and had a discussion with an informed professional (CB). Having information in these formats led to all seven interviewees changing to full support of data linkage. One teacher also initially felt ‘reluctant’ and ‘nervous’ about using identifiers without consent. However, when the split file process was explained she no longer had these concerns.

“From what we've talked about [in the interview], my views are very different [to] what perhaps I said in the original survey.” (Interviewee – father of 18-month-old twins born 26 weeks).

There was strong support for information on data linkage, in the future, to be available in different formats. (See quotes 4 and 5, table 3).

When

Quantitative survey results indicated that data linkage should only be discussed near to, or following discharge from the neonatal unit (Figure 3). Qualitative data showed that earlier on, new parents are worried about their baby’s survival and hence discussing data linkage into the future is unlikely to be appropriate.

“Definitely not in neonatal unit - too many emotions, concerns and unknowns whilst baby [is] in neonatal care” (Survey free text - mother of one-year-old born 30 weeks)

Theme 3: Looking to the future; the rights of young people

While the value of lifelong data linkage was acknowledged by participants, only 12% of survey respondents agreed this should be automatic (Table 2). The majority of survey respondents (60%), and all interviewees, indicated that individuals born preterm should be consulted at an appropriate age on on-going linkage of their data. (See quote 6, table 3).

DISCUSSION

Using a mixed methods approach to explore views of parents, adults born preterm and professionals on data linkage for research, we identified three themes. There was clear demand for better information on long term outcomes and strong support for data linkage with opt-out consent as a method of achieving this (theme 1). The importance of the right content, timing and format of information was highlighted (theme 2) and there was a strong feeling that individuals born preterm should be consulted, in the future, about linking their data beyond school-age (theme 3). Responses from parents and adults born preterm were similar.

Our findings of strong parental support for data-sharing and opt-out consent for research corroborate those from a previous study in 2011-2012. (19) This earlier study surveyed parents of preterm babies during admission to the neonatal unit; our study provides evidence of continued support into childhood and beyond. Both surveys identified small proportions of the target populations opposed to data-sharing if identifiers were used, or explicit permission was not sought. We found that support for data linkage is likely to be maximised if differing requirements of individuals, for the content and format of information are met. In terms of content, different levels of detail on key issues such as data security, were required. In terms of format, the availability of visual information and the opportunity for a discussion with an expert were important. Meeting these needs reduced concerns about the risks, and improved understanding of the benefits, of data linkage with use of temporary identifiers and opt out consent.

There were two findings that it appears have not previously been explored. Firstly, there was a clear message that data linkage discussions with parents would be insensitive during the neonatal stay, when survival is often the immediate concern. We will continue to explore ways to maximise communication following discharge, in community or hospital settings, as part of the NeoWONDER information dissemination programme. Secondly, our results clearly support children being consulted about linkage of their data beyond school-age. These findings are important for researchers and policymakers involved in data linkage across the life course and support national initiatives facilitating dialogue and involvement from the public to build trust. (20)

Our work emphasises the importance of co-production of resources. Based on our findings, we have developed multiple versions of parent/patient information leaflets; a short version in an accessible Frequently Asked Question format, and a longer more detailed version. (21) These have been approved by the Confidential Advisory Group (CAG) and Research Ethics Approval Committees (REC) (reference 21/EM/0130, IRAS ID 293603, CAG 21/CAG/0081). These regulatory bodies have also granted permission for the study to use personal identifiers for data linkage without the need for explicit consent from parents. Furthermore, we have co-produced a digital animation video to explain the complex data flows, (22) and have formed a young people's advisory group to co-lead future work consulting a larger group of individuals born preterm.

To our knowledge, the subject of data linkage has not been previously explored with this particular group of stakeholders. Other strengths of our work include our participatory and mixed methods approaches which helped ensure our research design and methods were feasible and acceptable and provided breadth and depth of data, and our timely co-production of new resources. Additionally, we achieved diversity within our pool of interviewees in terms of gestation at birth, region of the UK where neonatal care was received, experience of multiple and singleton births, mothers and fathers. (Supplementary S3). However, we were only able to include one adult born preterm, and two from ethnic minority backgrounds in the interviews. This was because our sampling was limited to the small pool of participants who expressed negative or uncertain views (Supplementary S3). Furthermore, despite efforts to include those with limited English proficiency in the study, we were unable to achieve this.

CONCLUSION

This mixed method study shows that with appropriate information parents, adults born preterm, and professionals are supportive of data linkage with opt out consent. Resources are being co-produced with parents, adults and teenagers born pre-term, and professionals to improve communication and understanding of routine data linkage.

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This study was funded through an NIHR Advanced Fellowship awarded to CB.

Competing interests

CB is funded through an NIHR Advanced Fellowship personal award.

Author contributions

The study was conceived and planned by CB, MS, TH, LJ, JK, TB, JL

Interviews were conducted by CB, MS, EvB

Data were prepared by CB, MS, EvB

Analysis was conducted by CB, MS, EvB

The paper was written by CB, MS, EvB, NM, TH, LJ, JK, TB, JL

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