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Research published!



We are delighted to share our recent publication in Archives of Disease in Childhood: Fetal and Neonatal Edition

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

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AIMS OF THE STUDY

We wanted to explore views on linking together data collected as part of routine care, for research on improving future outcomes of babies born premature.

WHAT WE DID

We held focus groups to design a survey for parents and adults born preterm



The online survey was advertised around the country



We invited survey participants who had expressed negative or uncertain views to an in-depth interview. We wanted to understand their concerns or uncertainties



We also held interviews with health professionals and teachers

WHAT WE FOUND

We had a fantastic response, with over 500 surveys completed. We held 12 interviews. Putting this all together, we found that three themes emerged:

1. There is clear demand for better information on long-term outcomes for babies born premature. Most participants were happy with data linkage and opt-out consent.

Those who were initially concerned were satisfied with the study's design after a more in-depth discussion of the data security and use of the data.

2. Providing the right information, in different formats, with the right level of detail, at the right time.

Data linkage should be discussed with families around the time of neonatal discharge home, but definitely not earlier during the neonatal unit stay.

3. Rights of the young person.

The person born preterm should be consulted on the use of their data once they are old enough.

With the right information, given at the right time, parents, adults born preterm and professionals are supportive of data linkage for research

Link to
the paper



**A huge thank you to all
who participated in the
study**



Learn more:
our video on
data linkage