

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

S1: Survey content

A) BACKGROUND DETAILS

These first quick questions will give us a bit of information about you; this helps us to know whether we have captured views from people with different experiences.

I am:

mother to a child born preterm

father to a child born preterm

an adult born preterm

other e.g. step parent, adult sibling: [free text box for further detail]

For parents only: How old is your preterm child/children (in completed years)? If more than one preterm child, please include all ages

[free text]

For adults born preterm only: How old are you?

[free text]

For parents only: What gestation (weeks) was your preterm child/children born?

[free text]

For adults born preterm only: What gestation were you born?

[free text]

What ethnicity best describes you?

Asian

Black

Chinese

Mixed

White

Other

Which part of the country did you receive the majority of neonatal care?

London

Southwest

South East

East Midlands

West Midlands

Yorkshire and Humber

North East

North West

East

Other

Outside UK

For parents only: Does your preterm child/children have ongoing health needs?

Yes, a lot

Yes, a few
No, none
Other

For parents only: Does your preterm child/children have educational needs?

Yes, a lot
Yes, a few
No, none
Other

B. IMPORTANCE OF LONG-TERM OUTCOMES

These next questions are to obtain your views on the general importance of long-term outcomes

How important do you think it is to have better information on how preterm children develop as they grow up (i.e. their long-term outcomes)?

Very important
Important
Quite important
Not important
Not sure

Please tell us a bit more about your answer

[Free text]

How important do you think information on longer term health is?

Very important
Important
Quite important
Not important
Not sure

How important do you think information on behavioural, psychosocial and development is?

Very important
Important
Quite important
Not important
Not sure

How important do you think information on educational progress is?

Very important
Important
Quite important
Not important
Not sure

How closely related do you think how healthy a child is and their learning or educational progress?

Very closely related
Related
Possibly related
Not related
Not sure

If you wish, please tell us a bit more about your answers
[Free text]

C: DATA LINKAGE AND ANONYMISED DATA

Health records have NHS numbers, and education records have Unique Pupil numbers. As these are not the same, we would need to use personal identifiers such as name, postcode, date of birth to link records. The identifiers are only used for the linkage; once linked, the identifiers are removed and the data becomes anonymous. This means that anyone looking at the data cannot find out who the individual children are in the data set.

The next few questions ask for your views on the reality of linking a preterm child's records.

How do you feel about linking together existing records to find out what happens to these preterm children as they grow up?

Yes, very supportive

Yes, supportive

I think so

No definitely not

Not sure

How do you feel about using your child's name, date of birth, postcode and other identifiers temporarily for linkage purposes?

I feel fine about this

I am a bit unsure about this

I do not agree with this

What are your concerns if any about this?

[Free text]

Some information may be thought "sensitive" like whether a child has special educational needs, an Education, health and care plan (EHCP) or free school meals. Would you be happy for researchers to use your child's "sensitive information", if it was anonymous?

Yes

No

Don't know

Whatever your answer, please explain why if you would like to

[Free text]

Till when do you think it is acceptable to link preterm children's data?

Lifelong

I agree with the principle of lifelong data linkage but would like the opportunity for my child to be consulted for their views

Until they have completed education

Until the age of 18 years as legally they will be an adult

I don't think it is acceptable ever

Other

D. USE OF ANONYMISED DATA WITHOUT CONSENT, NOTIFICATION AND OPT-OUT/DISSENT

As it would be impossible and impractical to seek permission (i.e. consent) from 90,000 families to link these data, we will seek permission from the Confidential Advisory Group (CAG) to link these data without consent (assuming parents and ex-patients are supportive).

However, we would want to try our best to let parents of preterm babies and ex-patients know that this is what we were doing, and give them a chance to opt-out if they do not wish for their data to be linked.

Would you be happy for researchers to use your child's electronic medical and school records for this reason, without consent, if they were always anonymous?

Yes

No

Don't know

E. MAKING DATA LINKAGE ROUTINE IN THE FUTURE

The ideal situation is for data to be linked going forwards for babies born beyond 2018 as well. We want to make sure we provide information at the most appropriate time. We know that too much information can be overwhelming, especially on arrival and during your time in the neonatal unit when there is lots going on. We want to understand your views about how and when discussion about data should take place.

What do you think about making data linkage routine going forwards for preterm babies?

Yes, should be done routinely

Maybe

No, I don't think this should happen

What are your concerns if any about this?

[Free text]

When do you think is an appropriate time to discuss the use of data and opt-out? Tick all that apply:

On admission to the neonatal unit

At the start of neonatal unit stay

During the middle of neonatal unit stay

At the end/discharge from neonatal unit stay

Weeks following discharge from neonatal unit stay

At follow-up outpatient clinics

Please tell us a bit more about your answers

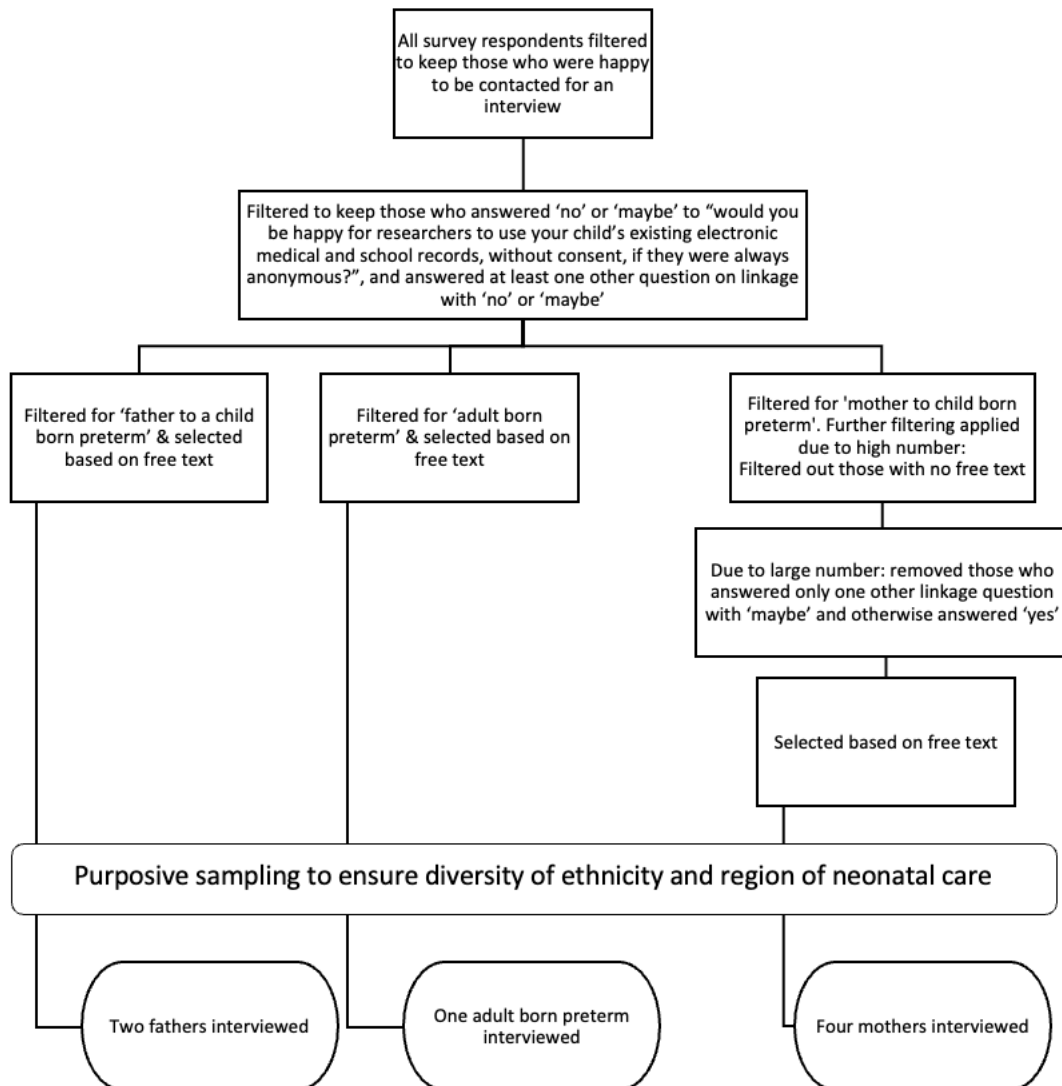
[Free text]

We would like to interview a small number of parents to further our understanding. Is this something you would be happy doing?

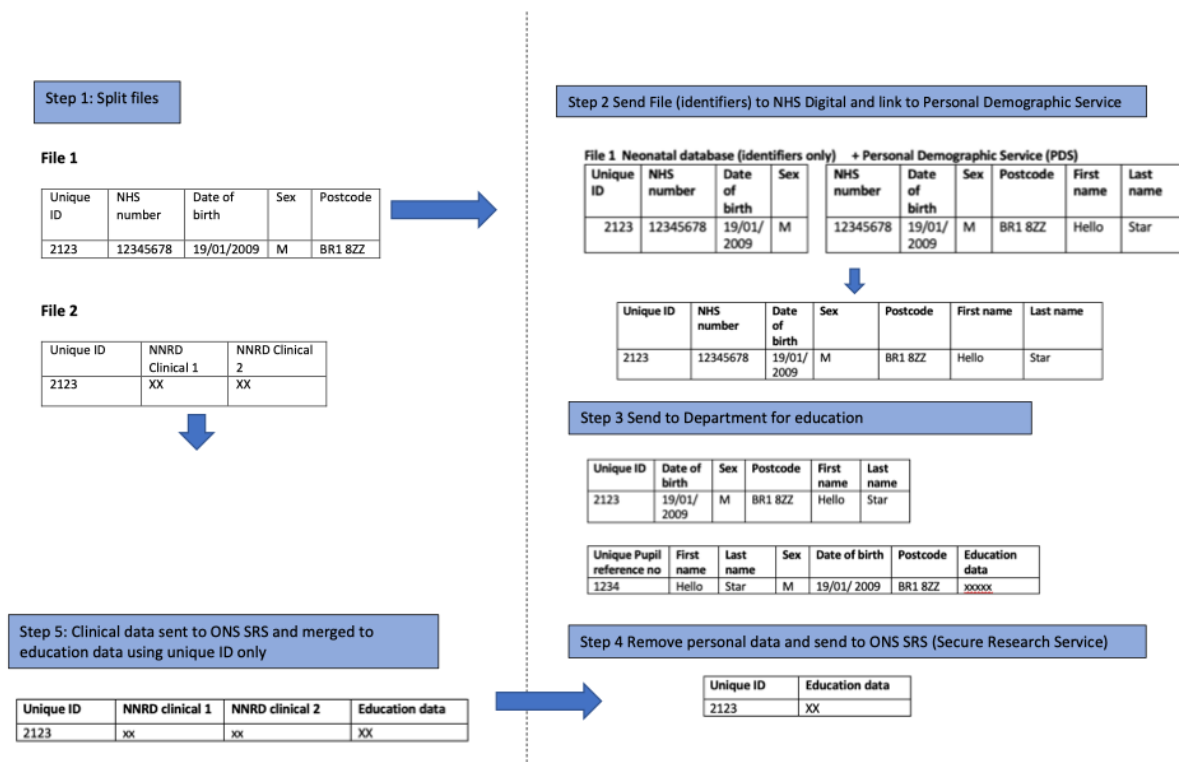
If so, please provide your email. Please be aware that if you provide your email address you potentially make your survey answers identifiable. We can assure you that no one other than the small research team will see your initial submission and we will remove your email address and save it separately to your survey as soon as we receive it.

If you would like us to inform you of the outcomes of this research or any outputs related to this research, please provide your email address.

S2: Process for selection for invitation to interview



S3: Flow diagrams used to explain data flows in interviews



S4: Characteristics of interviewees (parents of preterm-born children and adult born preterm)

Characteristic	Category	Number N=7
Relationship to preterm birth	Mother to a child born preterm	4
	Father to a child born preterm	2
	Adult born preterm	1
Singleton or multiple birth	Singleton	6
	Multiple	1
Gestation (if multiple children then earliest gestation)	25 – 27 + 6 weeks	5
	28 – 31 + 6 weeks	1
	32 – 36 + 6 weeks	1
Ethnicity of participant	Asian	2
	White	5
Region of majority of neonatal care	East	1
	Midlands	3
	London	2
	Wales	1
Current age of preterm-born child (eldest if more than one preterm-born child) [‡]	< 1 year	2
	1 – 5 years	3
	6 – 10 years	1
Current age of adult born preterm (years) [§]	20 – 29	1

[‡]n = 6

[§]n = 1

