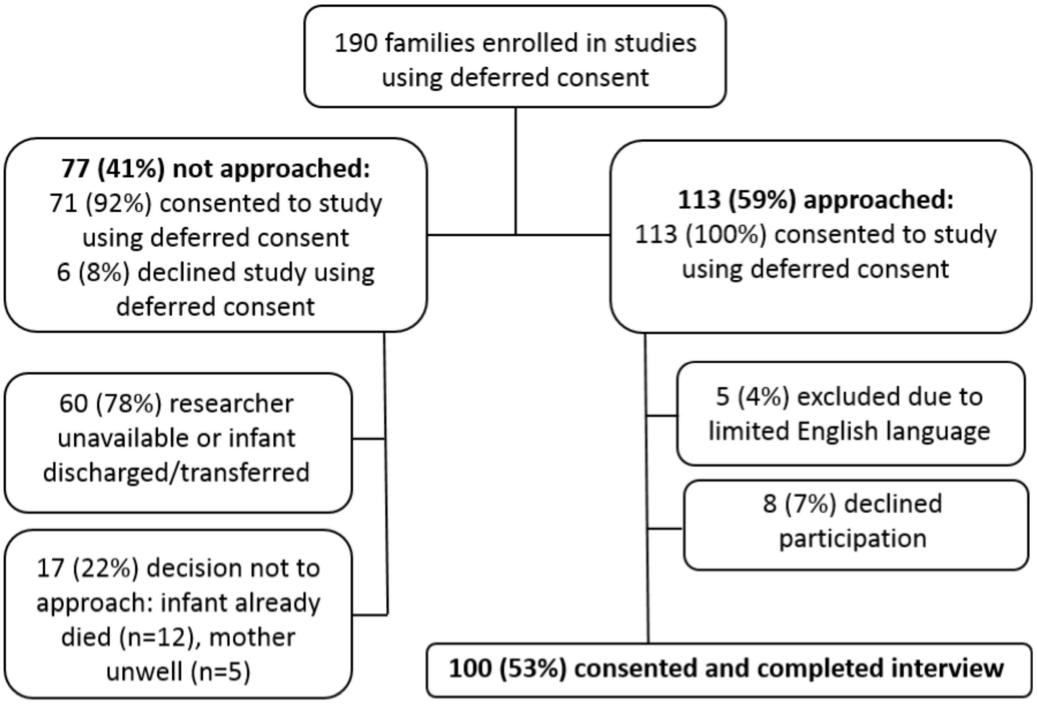
Supplementary material

Table: Studies running during recruitment that used Prospective Consent only

Study Title	Study Description	Clinical Trial Registration No.
Pronose	A randomized controlled trial of a Barrier Dressing to Reduce Nasal Injury in Preterm Infants	ACTRN12616000438459
Neo-ICog	Improving the understanding of immunity and coagulation in preterm infants, including the relevance of these systems to neonatal diseases	N/A
VICS	Victorian Infant Collaborative Study 2016/17 cohort	N/A
Epiprem	Epigenetic effects of preterm birth and neonatal interventions.	N/A
Optimist	OPTIMIST-A Trial: Minimally-invasive Surfactant Therapy in Preterm Infants 25-28 Weeks Gestation on CPAP	NCT02140580
e-PREM	The role of social risk in an early preventative care programme for infants born very preterm: a randomized controlled trial	ACTRN12606000252516
Wiggle Study	Non-invasive high frequency oscillatory ventilation to improve respiratory stability in preterm infants – a randomized crossover trial	ACTRN12616001516471
ProVIDe	The impact of protein IVN on development	ACTRN12612001084875
Skin2skin	Cerebral oxygenation during skin-to-skin care in preterm infants not receiving respiratory support	ACTRN12616000240448
N3RO	Docosahexaenoic Acid and Bronchopulmonary Dysplasia in Preterm Infants	ACTRN12612000503820
Side-Lying Feeding Study	In preterm infants receiving respiratory support does a side-lying position compared to a standard cradle-hold position improve physiological stability	ACTRN 12613000735752

Figure 1 Flow Diagram of Eligible Parents



Parental Questionnaire

Patient Information

Survey no: ☐☐☐ **Date of interview**: ☐☐:☐☐:☐☐

Parent interviewed: Mother ☐ Father ☐ Both parents ☐

Infant UR: ☐☐☐☐☐☐

Infant's DOB: ☐☐/☐☐/☐☐☐☐

Gender: Male ☐ Female ☐

Gestation: ☐☐ wk

Birthweight: ☐☐☐☐ g

Maternal UR: ☐☐☐☐☐☐

Maternal Age: ☐☐ years

Parity: **G** ☐☐ **P** ☐☐

Length of admission before birth: <12 hrs ☐

12 – 24 hrs ☐

24 - 72 hrs ☐

>72 hrs ☐

Name of Eligible Study	**Timing of consent** Antenatally/postnatally Prospective/Retrospective/ not discussed	**Consent given** Yes/No/ not applicable

Section A: General

A1. Which studies were you approached about?

(*Parents will be shown the research leaflet listing all current studies)*

List study names: ----------

Number of studies approached about: ☐☐

A2. Which of the studies did you agree that your baby could take part in?

List study names: ----------

Number of studies consented to: ☐☐

A3. Which of the studies did you not agree for your baby to take part in?

List study names: ----------

Number of studies declined: ☐☐

Section B: Retrospective consent

"*We always ask permission from parents for their baby to be involved in a study. This is called consent. Consent is sometimes asked for before a project begins and sometimes after the project begins. For most studies we would speak to you first and ask if your baby can join. In some circumstances when there is limited time e.g. around the time of birth or with emergency procedures, we would start the study and speak to you as soon as possible afterwards to explain the study and ask for your permission for your baby to continue being involved in the study. This is known as retrospective consent*."

Your baby was enrolled in the _____ study and you were approached about consent after this. (*If more than one study, each will be discussed individually and responses recorded on a separate page*)

B1. Did you agree to take part in this study? Yes ☐ No ☐

If **YES**, what were your reasons for saying yes? *(Select all that apply)*

- To benefit my baby (to continue with the treatment for my baby) ☐
- To help future babies ☐
- To help the researchers ☐
- Didn't think there was any harm attached ☐
- Saying no would affect the care my baby received in hospital ☐
- Baby already involved in study so agreed ☐
- Other (*please state)*_____

If **NO**, what were your reasons for saying no? *(Select all that apply)*

- Did not like this particular study ☐
- Did not want to be involved in any research studies ☐
- Too upset/stressed/pre-occupied at the time to fully consider the study ☐
- Did not understand what the study involved ☐
- Did not like that baby had been included in the study without talking to you prior to this ☐
- Had been approached about too many studies already ☐
- Other (*please state)*_____

Sloss S, *et al*. *Arch Dis Child Fetal Neonatal Ed* 2021; 106:258–264. doi: 10.1136/archdischild-2020-319974

B2: Do you think that if you had been approached about the same study before your baby was involved you would have given the same answer?

Yes ☐ No ☐ Unsure ☐

If **NO**, why not?

_____

_____

B3: For this study, to have obtained prospective consent, (consent from you before enrolling your baby in the study), we may have had to speak to you shortly before your baby's birth or very soon after your baby was born (within a couple of hours). Do you think this is preferable to the retrospective consenting process which you were involved in?

Yes ☐ No ☐ Unsure ☐

Any comments:

_____

_____

B4: Was there anything about the consenting process for this study you were unhappy with or thought could be improved?

Yes ☐ No ☐ Unsure ☐

If Yes, please describe_____

_____

B5: Did you and your partner discuss the decision for your baby being involved in this study?

Yes ☐ No ☐

If **YES**, Did you and your partner:

- Agree to give consent? ☐
- Agree to not giving consent ☐
- Disagreed but gave consent anyway ☐
- Disagreed and did not give consent ☐

Section C: Prospective consent

Your baby was enrolled in the _____ study and you were approached about consent before your baby was enrolled in this study. (*If more than one study, each will be discussed individually and responses recorded on a separate page*)

C1. Did you agree to take part in this study? Yes ☐ No ☐

If **YES**, what were your reasons for saying yes? *(Select all that apply)*

- To benefit my baby (to continue with one of the treatments for my baby) ☐
- To help future babies ☐
- To help the researchers ☐
- Didn't think there was any harm attached ☐
- Saying no would affect the care my baby received in hospital ☐
- Other (*please state)*_____

If **NO**, what were your reasons for saying no? *(Select all that apply)*

- Did not like this particular study ☐
- Did not want to be involved in any research studies ☐
- Were too upset/stressed/pre-occupied at the time to fully consider the study ☐
- Did not understand what the study involved ☐
- Other (*please state)*_____

Sloss S, *et al*. *Arch Dis Child Fetal Neonatal Ed* 2021; 106:258–264. doi: 10.1136/archdischild-2020-319974

C2: Was there anything about the consenting process for this study you were unhappy with or thought could be improved?

Yes ☐ No ☐ Unsure ☐

If Yes, please describe_____

C3: Did you and your partner discuss the decision for your baby being involved in this study?

Yes ☐ No ☐

If **YES**, did you and your partner:

- Agree to give consent? ☐
- Agree to not giving consent ☐
- Disagreed but gave consent anyway ☐
- Disagreed and did not give consent ☐

Section D: Number of studies to participate in

D1: Do you think there should be a limit to the number of studies where infants are enrolled and consent is obtained retrospectively?

Yes ☐ No ☐

If **YES**, What do you think this limit should be? _____

Why do you think there should be a limit?_____

D2: Would you prefer a single approach to discuss multiple studies together or to be approached about one study at a time?

Single ☐ Multiple ☐ Unsure ☐

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Section E: Parent details

E1: Ethnicity *(please tick one box)*

- Caucasian: (origins from Europe, Middle East, North Africa, (Arabic origins) Lebanese, Western Russia, South Russia, and Hispanics of Russia) ☐
- Asian: (origins in the Indian sub-continent OR Far East, Afghanistan) ☐
- African: (origins in any of the original peoples of Africa) ☐
- Aboriginal or Torres Strait Islanders ☐
- Other ☐ *Please Specify*:_____

E2: Language spoken:

- What is the main language spoken in your home? _____
- How many languages are spoken in your home? _____

E3: Education *(please tick one box)*

- Left school before year 12 ☐
- Completed year 12 ☐
- Higher education (diploma, graduate degree, post graduate degree) ☐

E4: Occupation *(please state)* _____

End of form

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