Supporting Information 1: Parent Survey, sections 1 and 2

Screening Question (NNU Graduate Parents only):
Are you the parent of a premature or sick baby?
  Yes
  No

Section 1: Parenting experience
1. Please tell us if you are a Mum or Dad
   I am a Mum
   I am a Dad

And now tell us a little about your child/ren
2. Do you have other children?
   Yes
   No

3a. How many weeks into the pregnancy was your baby born? (select one option for each child)

| Child 1 | Child 2 | Child 3 | Child 4 | Child 5 |
|---------|---------|---------|---------|---------|
| 23      | 23      | 23      | 23      | 23      |
| 24      | 24      | 24      | 24      | 24      |
| 25      | 25      | 25      | 25      | 25      |
| 26      | 26      | 26      | 26      | 26      |
| 27      | 27      | 27      | 27      | 27      |
| 28      | 28      | 28      | 28      | 28      |
| 29      | 29      | 29      | 29      | 29      |
| 30      | 30      | 30      | 30      | 30      |
| 31      | 31      | 31      | 31      | 31      |
| 32      | 32      | 32      | 32      | 32      |
| 33      | 33      | 33      | 33      | 33      |
| 34      | 34      | 34      | 34      | 34      |
| 35      | 35      | 35      | 35      | 35      |
| 36      | 36      | 36      | 36      | 36      |
| 37      | 37      | 37      | 37      | 37      |
| 38      | 38      | 38      | 38      | 38      |
| 39      | 39      | 39      | 39      | 39      |
| 40+     | 40+     | 40+     | 40+     | 40+     |

3b. Did they require care in a Neonatal Unit? (select one option for each child)

| Child 1 | Child 2 | Child 3 | Child 4 | Child 5 |
|---------|---------|---------|---------|---------|
| Yes     | Yes     | Yes     | Yes     | Yes     |
| No      | No      | No      | No      | No      |
3c. What is their current age? (select just one option for each child)

| Child 1 | Child 2 | Child 3 | Child 4 | Child 5 |
|---------|---------|---------|---------|---------|
| Days*   | Days*   | Days*   | Days*   | Days*   |
| 1 – 6   | 1 – 6   | 1 – 6   | 1 – 6   | 1 – 6   |
| 7 – 13  | 7 – 13  | 7 – 13  | 7 – 13  | 7 – 13  |
| 14 – 20 | 14 – 20 | 14 – 20 | 14 – 20 | 14 – 20 |
| 21 - 27 | 21 - 27 | 21 - 27 | 21 - 27 | 21 - 27 |
| 28 – 34 | 28 – 34 | 28 – 34 | 28 – 34 | 28 – 34 |
| 35 – 41 | 35 – 41 | 35 – 41 | 35 – 41 | 35 – 41 |
| 42 – 48 | 42 – 48 | 42 – 48 | 42 – 48 | 42 – 48 |
| 49 – 55 | 49 – 55 | 49 – 55 | 49 – 55 | 49 – 55 |
| 56 – 62 | 56 – 62 | 56 – 62 | 56 – 62 | 56 – 62 |
| 63 – 69 | 63 – 69 | 63 – 69 | 63 – 69 | 63 – 69 |
| 70 – 76 | 70 – 76 | 70 – 76 | 70 – 76 | 70 – 76 |
| 77 – 83 | 77 – 83 | 77 – 83 | 77 – 83 | 77 – 83 |
| 84 – 90 | 84 – 90 | 84 – 90 | 84 – 90 | 84 – 90 |
| 91 – 99 | 91 – 99 | 91 – 99 | 91 – 99 | 91 – 99 |
| > 100   | > 100   | > 100   | > 100   | > 100   |
| 1 month | 1 month | 1 month | 1 month | 1 month |
| 2       | 2       | 2       | 2       | 2       |
| 3       | 3       | 3       | 3       | 3       |
| 4       | 4       | 4       | 4       | 4       |
| 5       | 5       | 5       | 5       | 5       |
| 6       | 6       | 6       | 6       | 6       |
| 7       | 7       | 7       | 7       | 7       |
| 8       | 8       | 8       | 8       | 8       |
| 9       | 9       | 9       | 9       | 9       |
| 10      | 10      | 10      | 10      | 10      |
| 11      | 11      | 11      | 11      | 11      |
| 1 year  | 1 year  | 1 year  | 1 year  | 1 year  |
| 2       | 2       | 2       | 2       | 2       |
| 3       | 3       | 3       | 3       | 3       |
| 4       | 4       | 4       | 4       | 4       |
| 5       | 5       | 5       | 5       | 5       |
| 6       | 6       | 6       | 6       | 6       |
| 7       | 7       | 7       | 7       | 7       |
| 8       | 8       | 8       | 8       | 8       |
| 9       | 9       | 9       | 9       | 9       |
| 10      | 10      | 10      | 10      | 10      |
| 11      | 11      | 11      | 11      | 11      |
| 12      | 12      | 12      | 12      | 12      |
| 13      | 13      | 13      | 13      | 13      |
| 14      | 14      | 14      | 14      | 14      |
| 15      | 15      | 15      | 15      | 15      |

Other (please specify age for each child over age of 15 years)
4. Is your baby in NICU or SCBU at the moment? (select one)*
   
   My baby is in NICU
   
   My baby is in SCBU
   
   I have twins or more, with babies currently both in NICU and SCBU

**Section 2: Developmental concerns**

1. Do you have any current concerns for your child’s development?

   | Child 1 | Child 2 | Child 3 | Child 4 | Child 5 |
   |--------|--------|--------|--------|--------|
   | No     | No     | No     | No     | No     |
   | Yes    | Yes    | Yes    | Yes    | Yes    |

2. If yes, please describe them here

   (Free text response 300 character maximum)

**Supporting Information 2: Examples of Cohort 1 parent free text concern responses (in the words used by parents)**

- **Speech.**
- **Eating and crawling.**
- **She has erratic muscle tone, also an AVSD.**
- **My son has cerebral palsy and epilepsy so his development is delayed.**
- **Sensory processing concerns.**
- **Not doing what she should be for her age.**
- **Twin 1 long sighted, lazy eye. Twin 2 hypotonia and hypertonia.**
- **Ongoing physical development delays.**
- **Development is very slow compared to my other children. Only just today at 11 months did he hold his bottle for the first time. Still no speech and slow reaction to some things.**
- **I don’t have act specific worries yet because she is still so young, but I worry that later, she may not reach her potential in terms of intelligence because she was born so early.**
- **Global delay. Has been diagnosed ASD, ADHD, SPD.**
- **Childhood epilepsy.**
- **Bub is taking longer than expected to strengthen up his neck. He can barely hold it upright and doesn’t enjoy tummy time as his head just stays down.**
My son is 14 months old and although I'm told he is doing perfectly for his age I do have concerns that he is developing a little slower than others in regards to crawling, walking.

Child 1 has Aspergers. Child 3 has speech delay and food aversion issues.
My son has septo-optic dysplasia. He has been delayed in gross motor development.
Language skills. Comprehension is great but speech is very limited. Currently on wait list for paed.
Emotional (particularly anger) issues.
Sensory issues – textures, surfaces; developmental delay with her legs, arms and hand movement; speech delay.

Very delayed. Mild CP. Nystagmus
Slight delays with learning, handwriting etc.
Worried that my baby is developmentally delayed or has something serious wrong such as autism or cerebral palsy.
He has very mild cerebral palsy so has some fine and gross motor difficulties. He also seems to have some difficulties with concentration and impulsive behaviour.
Lack of vocabulary, only says dad.
When my son was born he weighed just 380 grams. At 3.5 years old he weighs just 10.5kg and is the 3rd%ile for height. His growth is a concern.
Potential hearing loss, respiratory issues.

My daughter had surgery for NEC and her wound de-hissed and herniated. The hernia will require surgery at a later date. Because she has very little abdominal muscles I am unsure how she will learn to crawl, if at all? She doesn't roll and hates tummy time. She has just recently learned to sit but gets tired and falls forward.
480 grams birth weight. Lacks concentration. Is def behind her twin sister. Has lung problems. Suffers now with illness.

Chronic lung disease, eye/hearing issues. Poor weight gain.
Speech. Had a few bleeds on the brain and also a cyst :( has only just started to run.
Delay in movement skills.
Still attend speech therapy but almost caught up. Barely eats anything - mainly white food.
Social anxiety, still a little delayed in eating.
He was only 1530g, so still waiting on him walking and he isn't saying any words yet. His eyes are being monitored as they have a slight lean.

ASD, SPD, ADHD.

Global developmental delay. Autism spectrum disorder.
Still struggling with feeding and probably needs an NGT again just for night feeds. Also, a little behind physically, but tracking normally.

Weight gain.

Speech, walking.

He has left vocal cord palsy so his speech is delayed. He has a dislocated hip so he’s not crawling yet.

He has chronic lung disease so he is on oxygen, and he is PEG feeding.

Had 2 lots of grommets. Hearing was impaired due to glue ear so am worried about speech delay, but not confirmed yet.

Twin 1 delayed speech and difficulties with low frustration tolerance. Twin 2 microtia. Just weaned from NGT. Not walking yet, only cruising. Only babbles, likely due to hearing impairment. Is the height and weight of an 18 month old.

Twin 1 quite delayed in speech and social development. She's been diagnosed with sensory processing disorder. Twin2 also delayed in speech but to a lesser extent. He has been diagnosed with mild cerebral palsy in his legs plus dysphagia.

Mild developmental delay, unspecified.

Child 1: ADHD, ODD, PDDNOS. Child 4: cerebral palsy.

I just really worry as my son will be 1 year corrected in a week and has no interest in walking.

Noonan syndrome diagnosed at 4 months old. Struggled with all aspects of development from eating to beginning to walk at age 19 months. Has several ongoing health issues that are monitored regularly.

She is a little slower at hitting some of the milestones but is still within the 'normal' range.

Slower at speech than his twin brother.

He’s got GDD.

Weekly physio for hypertonia in legs and regular OT & speech. Follow-up with orthopaedics for late DDH. Waiting for child development appointment for diagnosis.

Physiological development due to low birth weight.

Speech delay / issues, hearing concerns, feeding issues, behavioural issues, sensory issues.

The child has no speech or language.

Not walking or talking.

Optic nerve hyperplasia. Recurrent meningitis. Epilepsy. Delayed speech and food issues.

Abbreviations relating to parent quotes: ADD, attention deficit disorder; ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; AVSD, atrioventricular septal defect; CP, cerebral palsy; DDH, developmental dysplasia of the hip; GDD, global developmental delay; NEC, necrotising enterocolitis; NGT, nasogastric tube; ODD, oppositional defiant disorder; OT, occupational therapy; paed, paediatrician; PDDNOS, pervasive developmental disorder not otherwise specified; PEG, percutaneous endoscopic gastrostomy; SPD, sensory processing disorder.
Supporting Information 3: Examples of Cohort 2 parent free text concern responses (in the words used by parents)

Vision - ROP surgery. Brain development - bleeds in ventricles. Lung capacity - chronic lung.
Worried that the 'normal' health issues of premature babies (ie: desats, brady's etc) will impact my (twin) boys' development.
He had bleeds on the brain when he was born due to being resuscitated and we won't know re: his development until he is 2-3 years old.
Short term: growth/size, establishing oral feeding, eyes. Long term: impact of steroids on development, achievement of milestones around all developmental areas (communication, sensory, feeding, gross/fine motor etc).
Concerns regarding hitting the usual developmental goals, breast feeding etc. Longer term: walking, crawling, speech, solid feeding.
Only general concerns regarding eyesight, hearing and mobility, but no significant reason for those concerns. Underlying concern about cognitive development given prematurity and the potential for delays, along with their impact.
Further feeding issues.
Mainly whether from full term would development be similar or not as much as a baby born at full term in terms of timing of milestones etc.
General concerns about lung, eyes and mental development.
Prematurity affecting development. Brain bleeds. Reflux.
Cerebral palsy.
If my baby would have any long-term consequences of being born prematurely and if he would have any significant developmental problems.
Her eye development (good so far) and her lungs as she still requires oxygen.
Vision, hearing, overall health. Developmental delays, processing delays.
Will her journey over the past week impact her development in the future? Can it impact her, or is it more common in babies born earlier? What sort of impact could there be on development?
Hearing, vision, speech and overall health in general.
[My daughter] has a reservoir to drain fluid and I worry how the bleed in her ventricles will affect her development.
Lack of oxygen at birth - not sure how this will affect his development - if at all.
I am unsure how [my son's] early birth will affect his developmental milestones.
Her weight.
Will being premature affect my daughter's intelligence? Will her motor function be affected?
Every parent worries about child’s development. Same concerns as a full-term baby. Future learning and physically.

Long-term development is a significant concern when I've had a premature baby: ie learning difficulties etc. How prematurity can affect learning outcomes in later life ie: neurological impairment. Possible effect of oxygen upon eyesight etc. ADHD. Increased risk of SIDS

I'm worried about her general physical and cognitive development. I've heard a lot of stories and risk factors that come with premmies.

His right leg cannot bend very well. Brain development. Muscle development.

Meningitis - long term development.

She's on oxygen and they are unsure of what is wrong with her and when she will be well.

If he will have any problems learning to walk as he was breech. If he will have any problems with breathing due to being so prem.

I'm unaware of milestones that my child should be meeting at this young age - so I am concerned that I don't know what he should and should not be doing.

Being a premmie baby I am concerned about his development. Will he be behind other babies? Will he learn as quickly?

Abbreviations relating to parent quotes: ADHD, attention deficit hyperactivity disorder; bradys, bradycardic episodes; desats, oxygen desaturation episodes; prem, premature (GA < 37 weeks’ gestation); ROP, retinopathy of prematurity; SIDS, sudden infant death syndrome; SPD, sensory processing disorder.