Neurodevelopmental follow-up of preterm infants: current practice for infants at a tertiary neonatal centre

Meghan Ealish Sandle, Maria Saito Benz, Laura Port, Max Berry

ABSTRACT

AIM: To characterise neurodevelopmental surveillance, assessment and outcomes for infants at risk of adverse neurodevelopment and inform targeted surveillance of infants discharged from a regional tertiary neonatal centre.

METHODS: A retrospective study of developmental follow-up of 106 vulnerable infants born either preterm (23–29 weeks gestation, n=96) or at ≥30 weeks gestation with low birth weight (<1,200 grams n=10) admitted to our tertiary Neonatal Intensive Care Unit between January 2011 and December 2015. Infants transferred to other regions before two-years corrected postnatal age were excluded. Local health records were reviewed to determine neurodevelopmental follow-up, input and outcomes.

RESULTS: Almost all (98%) of high-risk infants received at least one follow-up visit by a visiting neurodevelopmental therapist following discharge from the neonatal unit, and 73% of infants received early developmental follow-up in line with international recommendations. Ninety infants (87%) were seen until at least two years post term, at which point 61 (68%) had typical development. At five-years post term, 23 (26%) of the 89 infants remaining in the region had been diagnosed with a developmental disability, for which global developmental disability was the most common diagnosis (19 infants).

CONCLUSION: Routine neurodevelopmental surveillance of vulnerable infants from our tertiary catchment has high coverage, with most infants receiving regular developmental assessment. However, universal developmental screening is resource intense, and overall rates of diagnosed neurodevelopmental impairment are relatively low. Better early identification of infants most at risk using earlier assessment tools may help to stratify and target follow-up to allow resources to be allocated more effectively and reduce the follow-up burden for infants at lower risk of developmental concerns.

In 2016, there were 60,000 live births in New Zealand, of which just over 4,500 (7.5%) were of infants born preterm, before 37 weeks gestational age. Preterm infants are at increased risk of adverse neurodevelopmental outcomes, including developmental delay, intellectual disability (ID), autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and mood and emotional problems. These difficulties have implications across an individual's life and affect education, employment and wellbeing. Preterm birth can therefore impact on the life-course and create long-term disparities in health, wellbeing and economic outcomes for children and young people, their families and communities.

Advances in obstetric and neonatal care have led to increased survival rates of extremely preterm (≤28 weeks gestational age) and low birth weight infants (LBW; birth weight <1,200 grams). Although overall rates of neurodevelopmental disability vary internationally, they are universally high and have not changed significantly over the preceding 10 years. Additionally, an earlier the gestational age at birth leads to a greater risk of adverse neurodevelopmental
outcome. Therefore, as the threshold for active intervention at the extremes of gestational age and birth weight continues to fall, accurate identification of neurodevelopmental risk is essential in order to provide targeted neurodevelopmental follow-up and intervention, especially within publicly funded health care systems, such as in Aotearoa New Zealand.

In this group, the objectives of neurodevelopmental surveillance include developmental monitoring and prompt recognition of neurodevelopmental difficulties, which in turn enable the timely provision of appropriate intervention. This capitalises on early developmental neuroplasticity and improves the child’s neurodevelopmental trajectory. Early developmental intervention in preterm infants is associated with improved motor and cognitive outcomes. In infants with cerebral palsy, earlier diagnosis and earlier intervention have a demonstrably positive effect on the wellbeing of caregivers.

Longitudinal surveillance should assess growth, neurological and motor function, cognitive development, language, behaviour, functional status and family resources. Consequently, universal screening of high-risk infants, many of whom go on to follow a standard neurodevelopmental trajectory, carries a significant time and resource burden. There is also a risk to families of on-going “medicalisation” of otherwise well infants. This may adversely impact psychological and emotional wellbeing for the child’s caregivers.

These financial and other costs associated with screening infants with typical neurodevelopment nonetheless need to be balanced with the therapeutic advantage of early identification and intervention within the sensitive period of neuroplasticity in early infancy.

Internationally, many resource-rich countries provide tertiary-level care to preterm/LBW infants. They follow various strategies for neurodevelopmental follow-up of high-risk infants. The most effective way to provide appropriate developmental screening and resource allocation has yet to be determined within Aotearoa New Zealand, where there are complexities relating to rurality, access to specialist services and a resource-constrained health system. Despite these challenges, Aotearoa New Zealand must prioritise equitable access to appropriate neurodevelopmental surveillance and intervention for developmental follow-up. It also must meet its obligations under Te Tiriti o Waitangi (Treaty of Waitangi) and provide culturally appropriate models of care to achieve equitable health outcomes for Māori.

We therefore need to quantify the burden of neurodevelopmental difficulties faced by children born extremely preterm in Aotearoa New Zealand. This is necessary to help develop a national consensus and inform a targeted approach to screening.

In the UK, the National Institute for Clinical Excellence (NICE) published guidelines in 2017 for the developmental follow-up for children born preterm. These guidelines recommend enhanced surveillance for infants born <30 weeks gestation until at least two-years post term, as well as a minimum of two face-to-face visits in the first year and a detailed developmental assessment at two-years corrected post-term age (CPA).

Our Neonatal Intensive Care Unit (NICU) provides regional tertiary care for infants from 23 weeks gestational age. All infants born <30 weeks gestation or birth weight <1,200 grams are routinely referred for follow-up by visiting neurodevelopmental therapists (VNDTs) from our hospital-funded Child Development Service. VNDTs provide developmental surveillance and support for at-risk infants through home visits, regular assessment using standardised developmental tools and early intervention. VNDT follow-up is in addition to routine Well Child services provided for all infants in Aotearoa New Zealand and specialist neonatologist medical review, which typically continues for at-risk infants until around three years of age.

The aim of this study was to determine the practice of neurodevelopmental surveillance and the prevalence of developmental difficulties within a contemporary cohort of at-risk infants. This will help inform strategies to better rationalise our current model of care in the context of an increasing high-risk infant population and competing priorities within New Zealand’s public health care system.
Methods

We carried out retrospective study of the developmental follow up for preterm/LBW infants discharged from Wellington NICU into our district health board (DHB) catchment area.

Inclusion criteria were infants in-born in Wellington Regional Hospital between January 2011 and December 2015 with a gestational age (GA) at birth <30 weeks and/or a birth weight (BW) <1,200 grams. This birth weight and gestational age were chosen to reflect the referral threshold to the child development service as per our local policy. We excluded infants born or dominated in a different DHB (ie, those discharged back to their local DHB for all follow-up) or who moved and were referred to a different DHB within two-years post term.

Data were obtained from the infant’s interdisciplinary health records within the DHB and included NICU inpatient notes, medical clinical letters and community notes and reports from the Child Development Service. Demographic information was collected for each infant, including gestational age at birth, birth weight, sex and prioritised ethnicity, as recorded in the patient records. Prioritised ethnicity data assigns a single ethnic group to individuals. This system is frequently used for health and disability data.17

Socioeconomic status was determined by the New Zealand Index of Deprivation (NZDep) for the infant’s address at birth. The NZDep measures social deprivation based on small geographical areas, with the least deprived areas scoring 1 and the most deprived areas scoring 10.9

Follow-up information included VNDT input, length of follow-up, referral to other services, results of standardised assessment and discharge from child development service.

Neurodevelopmental assessment was performed using the Bayley Scales of Infant Development (BSID), the most well characterised assessment of global development in infants born preterm.18 Bayley III (current edition of BSID at time of study) is administered to children aged between one and 42 months as a one-on-one assessment by a trained examiner; three scales are administered which assess cognition, language (receptive and expressive communication subtests) and motor (fine motor and gross motor subtests). BSID can be used to identify developmental delay. A composite score less than one standard deviation from the normative mean (<85) representing development delay on that scale.19

Developmental delay or concerns were defined by BSID scores (composite score <85) and/or VNDT report. Typical development on BSID performed at any age was defined by composite score on all scales ≥85.

Developmental outcomes at five-years post term were obtained for infants recorded as still living within the region. Diagnosis of developmental disability was determined from the child’s health records, including assessment by psychologist and/or paediatrician. Global developmental disability was diagnosed using standardised assessment (Griffith III) and ASD diagnosed by specialist multidisciplinary assessment.

Ethical approval for this study was prospectively obtained by the Child Health Research and Audit Committee at Wellington Regional Hospital.

Results

Between January 2011 and December 2015, 115 infants born at GA <30 weeks and/or BW <1,200 grams in Wellington NICU were discharged to the local region. Nine were excluded because their families relocated out of area and they were referred to another developmental follow-up programme within two-years post term. We analysed the outcomes for 106 infants.

Infant characteristics

Key demographics are listed in Table 1. Ninety-six infants (91%) were born at GA <30 weeks. Of these, 79 also had low birth weight (BW <1,200 grams). Ten infants born ≥30 weeks were eligible for developmental follow-up due to low birth weight. The median gestational age was 27+6 weeks (range: 23+0–31+2 weeks) and median birth weight was 945 grams (range: 410–1,765 grams).

Over half the infants (57%) were male. Most infants (60%) were of European ethnicity and 12% were Māori, according to registered prioritised ethnicity data. The cohort’s NZDep range, based on address at

ARTICLE
Table 1: Demographic characteristics of 106 infants born in Wellington NICU at <30 weeks GA and/or < 1,200g BW.

<table>
<thead>
<tr>
<th>Infant characteristic</th>
<th>N (%)</th>
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<tbody>
<tr>
<td>Preterm (&lt;30 weeks GA)</td>
<td>96 (91%)</td>
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<tr>
<td>LBW (&lt;1,200 grams)</td>
<td>89 (84%)</td>
</tr>
<tr>
<td>&gt;30 weeks GA and &lt;1,200 g</td>
<td>10 (9%)</td>
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<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>60 (57%)</td>
</tr>
<tr>
<td>Female</td>
<td>46 (43%)</td>
</tr>
<tr>
<td><strong>Prioritised ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>16 (15%)</td>
</tr>
<tr>
<td>European</td>
<td>64 (60%)</td>
</tr>
<tr>
<td>Māori</td>
<td>13 (12%)</td>
</tr>
<tr>
<td>MELAA(^1)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Pacific</td>
<td>12 (12%)</td>
</tr>
<tr>
<td><strong>NZDep index</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>27 (26%)</td>
</tr>
<tr>
<td>2</td>
<td>10 (9%)</td>
</tr>
<tr>
<td>3</td>
<td>13 (13%)</td>
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<tr>
<td>4</td>
<td>7 (7%)</td>
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<tr>
<td>5</td>
<td>14 (13%)</td>
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<tr>
<td>6</td>
<td>3 (3%)</td>
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<tr>
<td>7</td>
<td>2 (2%)</td>
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<tr>
<td>8</td>
<td>10 (9%)</td>
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<tr>
<td>9</td>
<td>10 (9%)</td>
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<tr>
<td>10</td>
<td>10 (9%)</td>
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</tbody>
</table>

\(^1\)Middle Eastern, Latin American, African

\(^2\)New Zealand Index of Deprivation- based on maternal address at time of birth
time of birth, was 1–10, with decile 1 (least deprived) being the most frequent.

**Neurodevelopmental follow-up**

All 106 infants were referred to the Child Development Service following discharge from NICU. Overall, post-discharge neurodevelopmental follow-up rates were high. One hundred and four infants (98%) received at least one face-to-face follow-up visit by a VNDT.

Three infants died within two-years post term (Figure 1). Two had had developmental concerns identified. The third was significantly unwell with multiple admissions to hospital and no formal neurodevelopmental assessment was documented. All three infants were excluded from further analysis.

Ninety of the 103 surviving infants (87%) received VNDT input until at least two-years CPA. Of these, 21 received follow-up and intervention for at least three years post term, 13 received follow-up for less than two years and two were never assessed by a VNDT (one family declined follow-up and one family was uncontactable).

Table 2 shows the differences in the baseline characteristics between two groups of infants: those who received no follow-up or follow-up for less than two-years CPA, and those who received neurodevelopmental surveillance until at least two-years CPA. Both groups had a similar median gestation and birth weight. Although the numbers are small, the group of infants who received follow-up for less than two-years included a higher proportion of males, a higher proportion of infants with an NZDep index >6 and a higher proportion of Māori infants.

The median age of discharge from VNDT follow up was 25 months post term age.

Most infants received follow-up that met the international NICE recommendations. Seventy-five infants (73%) received at least two face-to-face visits in the first year and detailed developmental assessment around two-years CPA. Similarly, most infants (90/103; 87%) had at least one BSID assessment during the period of developmental surveillance. Sixty-two were assessed twice at approximately 12-month intervals, and four had three assessments.

In total, 152 individual BSID assessments were performed for preterm/LBW infants over the five-year study period.

Of the 90 infants who received BSID, 29 (32%) were identified to have a developmental delay (composite score <85 on any scale) on at least one of their assessments. All infants received the Bayley III edition. BSID was not completed where families were not able to be contacted or did not attend scheduled appointments.

Fifty-seven infants had additional assessment or input from another member of the Child Development Service. This was most commonly for review or for support from speech and language therapy (Figure 2).

**Neurodevelopmental outcomes**

Over half the infants (61/101; 60%) who received neurodevelopmental follow-up and at least once visit from VNDT had no developmental difficulties identified during their period of follow-up. Developmental concerns were recorded for 40 infants (42%). Developmental delay on standardised testing (BSID score <85) was observed in 29. Isolated language delay was present in six, isolated motor delay in eight and delays in more than one developmental domain in 15. A formal BSID assessment was not performed for two, but on observation and history they were found to have a language delay. The developmental concerns for the remaining nine infants related to specific areas such as gross motor or expressive or receptive language skills, but their overall composite scores on BSID were normal.

Of the 90 high-risk infants followed-up for at least two-years, 60 (67%) had age-appropriate development at two-years CPA. This includes eight infants who had earlier developmental concerns identified but typical development at their two-year assessments.

There were 89 children from the cohort who were recorded as domiciled within our DHB catchment at age five years. The prevalence of known developmental disability for these children at five years CPA, as determined from their current electronic health records, is shown in Figure 3.

Of these 89 children, 23 (26%) had been diagnosed with a developmental disability by age five (global developmental disability was the most common diagnosis (n=19)). Five had ASD and all but one was also diagnosed with global developmental disability. Three had cerebral palsy. Twenty-two had developmental delays on BSID or clinical
Figure 1: Follow-up of infants discharged from tertiary neonatal unit to local neurodevelopmental screening (n=106).

106 infants

- 1 infant died: 7 months CPA (Respiratory complication)
- 1 infant died: 12 months CPA (Respiratory complication)
- 1 infant died: 23 months CPA (Gastrointestinal complication)

103 surviving infants to 2 years CPA

- 2 infants (2%) received no VNDT follow up
- 11 infants (11%) received VNDT follow up for < 2 years CPA
- 90 infants (90%) received VNDT follow up until at least 2 years CPA

- 8 infants: lost to follow up
- 1 infant: Family declined further follow up
- 2 infants: Reason unknown
- 60 infants (67%) discharged with age appropriate development
Table 2: Characteristics of infants in neurodevelopmental follow-up programme for less than and more than two-years CPA (n=103).

<table>
<thead>
<tr>
<th></th>
<th>Median GA (weeks+days)</th>
<th>Median BW (grams)</th>
<th>Sex N (%)</th>
<th>NZDep index N (%)</th>
<th>Prioritised ethnicity N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2 years development follow-up (n=13)</td>
<td>27±3</td>
<td>1062</td>
<td>Male: 9 (70%) Female: 4 (30%)</td>
<td>1–5: 7 (54%) 6–10: 6 (46%)</td>
<td>Asian: 1 (8%) European: 7 (54%) Māori: 4 (30%) MELAA: 0 (0%) Pacific: 1 (8%)</td>
</tr>
<tr>
<td>≥2 years development follow-up (n=90)</td>
<td>27±7</td>
<td>943</td>
<td>Male: 49 (54%) Female: 41 (46%)</td>
<td>1–5: 62 (69%) 6–10: 28 (31%)</td>
<td>Asian: 15 (17%) European: 55 (61%) Māori: 8 (9%) MELAA: 1 (1%) Pacific: 11 (12%)</td>
</tr>
</tbody>
</table>

Figure 2: Utilisation of Child Development Service by vulnerable infants following NICU discharge.

* = for at least two-years post term.
assessment during their earlier neurodevelopmental surveillance. The twenty-third infant, who had initial follow-up until eight-months CPA and no developmental concerns at that time, was subsequently lost to follow-up. They were re-referred to the Child Development Service aged two and half and assessed and diagnosed with ASD.

Table 3 shows the characteristics of children with and without known developmental disability at five years. Children diagnosed with developmental disability had a lower average gestational age and weight at birth. The group of children with developmental disability had a higher proportion of males than the group without developmental disability, and a higher proportion of children with an NZDep index >6. The ethnicities of children were mostly similar in each group, except for Māori: there were relatively more Māori children with than without a developmental disability (17% verses 7%).

**Discussion**

We have demonstrated that the majority of high-risk infants enrolled in a post-discharge surveillance programme in a single tertiary NICU are free of neurodevelopmental problems at age two-years CPA.

Although “optimal” neurodevelopmental surveillance remains uncertain for non-stratified populations of high-risk infants, internationally recommended best practice suggests a minimum of two face-to-face visits in the first year and a detailed developmental assessment at two-years CPA. In practice, this represents a substantial ongoing burden of medical supervision for the infants, their family and whānau.

In our region, over a five-year period, nearly all preterm/LBW infants discharged from NICU who were eligible for neurodevelopmental follow-up received at least one face-to-face visit by a specialised developmental therapist. Most infants received monitoring that was consistent with requirements set out by international standards and until at least two-years corrected postnatal age. This rate of follow-up is higher than in a contemporaneous study in Australia that showed 50% of extremely preterm/LBW infants had received developmental follow-up until two-years post term.20

High rates of compliance with screening reassure us that the majority of these infants are doing well and enable us to discuss how a stratified screening approach might support those in need without burdening families with low-yield medical appointments.

One strategy to enhance the efficiency of developmental follow-up involves tools for earlier assessment. The general move-
Gait and movement assessment (GMA) is a non-invasive tool that analyses infant movement patterns in the first few months of life to determine the risk of later developmental disability. GMA is highly sensitive for detecting risk of cerebral palsy and has been shown to allow much earlier diagnosis than traditional approaches. GMA assessment can also help predict adverse cognitive and language outcomes.

Routine use of GMA in preterm/LBW infants was recently implemented in our service. It allows for early identification of at-risk infants and offer early, targeted intervention and clearly has a place in the model of care for developmental follow-up in Aotearoa New Zealand.

In our study population, most infants received at BSID assessment during the period of developmental follow-up. BSID is widely used for global neurodevelopmental assessment in this population. However, it is costly and time consuming to perform, with each assessment requiring 30–90 minutes of child interaction alone. In this study period, 152 BSID assessments were performed at around 12- and 24-months CPA, yet two thirds of these infants scored within the typical range across all scales. The use of BSID as a universal assessment tool in neurodevelopmental follow-up programmes, however is limited by concerns about under-diagnosis of developmental disability and its ability to predict later cognitive and motor impairment. Crucially, identification of problems following BSID at 12 or 24 months of age may be too late to guide targeted early intervention during the period of maximal neuroplasticity.

Since recent improvements in perinatal care have increased the number of infants meeting the requirements for neurodevelopmental follow-up and considerably increased demand on our resource-constrained system, it is important that we safely prioritise infants who are most in need. The prevalence of known developmental disability in our study population was 26%, which is similar to estimates from other studies, and therefore the majority of infants did not have a diagnosis of developmental disability and were discharged from surveillance with normal development. These data reassure us of the safety of rationalising follow-up for neurodevelopmental impairments.

Given the importance of accurate and early detection of developmental disability for infants and their families, it is critical that there is a consistent and universal approach to neurodevelopmental surveillance that maximises benefit in a

Table 3: Characteristics of children with and without developmental disability at five years CPA (n=89).

<table>
<thead>
<tr>
<th>Developmental Disability (n=66)</th>
<th>Median GA (weeks)</th>
<th>Median BW (grams)</th>
<th>Sex N (%)</th>
<th>NZDep index N (%)</th>
<th>Prioritised ethnicity N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No developmental disability</td>
<td>28^a</td>
<td>988</td>
<td>Male: 34 (52%)</td>
<td>1–5: 46 (67%)</td>
<td>Asian: 9 (14%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Female: 32 (48%)</td>
<td>6–10: 20 (33%)</td>
<td>European: 42 (64%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Māori: 5 (7%)</td>
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<td>MELAA: 0 (0%)</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Pacific: 9 (14%)</td>
</tr>
<tr>
<td>Developmental disability</td>
<td>25^a</td>
<td>799</td>
<td>Male: 15 (65%)</td>
<td>1–5:11 (48%)</td>
<td>Asian: 3 (13%)</td>
</tr>
<tr>
<td>(n=23)</td>
<td></td>
<td></td>
<td>Female: 8 (35%)</td>
<td>6–10: 12 (52%)</td>
<td>European: 13 (57%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Māori: 4 (17%)</td>
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<td></td>
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<td>MELAA: 0 (0%)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Pacific: 3 (13%)</td>
</tr>
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</table>
resource-constrained environment, such as Aotearoa New Zealand. Aotearoa New Zealand is also a geographically diverse country of low population density where access to neurodevelopmental follow-up for preterm infants varies.\(^3\) In certain areas, logistical problems, including limited access to resources and funding, may further impact a family’s ability to attend follow-up for neurodevelopmental screening. Developing services for the early identification of infants at high risk of developmental disability, and targeting resources for intensive therapies during the window of brain neuroplasticity, needs to be a priority.

Although most infants in this study did not have developmental concerns identified within the period of follow-up, the input from neurodevelopmental therapist extends beyond developmental screening. In addition to assessment, VNDTs provide therapy, engage with families, create long-term relationships and support infant development and parental interactions. This early developmental support may have reduced the severity or frequency of developmental difficulties within this group of high-risk infants. Even for infants who progress along normal developmental trajectories, this input may be beneficial in terms of encouraging attachment and positive parenting, critical “non-medical” elements that may have been disrupted as a consequence of the early NICU environment\(^3\) but are linked to improved cognitive outcome and resilience.\(^3\)

Access to equitable and culturally appropriate follow-up management also needs consideration. Māori babies are more likely to be born preterm, especially <28 weeks GA, compared to non-Māori.\(^3\) In this study, 12% of infants were Māori according to prioritised ethnicity. Although numbers were small, there was a higher proportion of Māori represented in the group of children who received a shorter duration of neurodevelopmental follow-up and the group with a developmental disability at age five years. The design and implementation of neurodevelopmental follow-up programmes therefore requires a culturally safe, whānau-centred approach in partnership with Māori to uphold the principles of Te Tiriti o Waitangi and are an opportunity to develop Kaupapa Māori health services, reduce inequity and improve outcomes.

This study is limited by being retrospective and relying on accurate documentation in medical notes. Although data were collected from a five-year period, the number of infants in this group was relatively small compared to the large-cohort studies used to determine neurodevelopmental outcomes in at-risk infants internationally. The prevalence of developmental disability in this cohort may be underrepresented due to diagnosis being made after the age of five years, which may occur despite normal BSID assessment\(^3\) or in a different setting such as education or mental health services. Diagnosis of disorders such as ADHD, DCD and mood and emotional disorders, and in some cases ASD, may not be made until the child is older and after the period of initial neurodevelopmental screening.

Developmental outcomes were not available for the 13 infants (12%) who did not receive neurodevelopmental follow-up or who were seen for less than two years. Infants who transferred to developmental screening programmes in other regions within the two-year follow-up period were excluded as follow up data were not available. The longer-term outcomes for the 17 children who were no longer living in the region at age five were not known. The generalisability of our outcome data to the wider preterm/LBW population is therefore limited by potential baseline differences between the groups of infants who remain living in an urban centre and have received regular follow-up compared to infants who live in more rural regions, who have moved between regions or who did not complete routine neurodevelopmental follow-up.

There is clearly a need for national cross-sector datasets to provide accurate, complete long-term outcome data for preterm infants in New Zealand.

**Conclusion**

At-risk preterm/LBW infants cared for in a single tertiary NICU and domiciled within catchment for community follow-up are being referred for, and receiving, neurodevelopmental surveillance. Although rates of developmental disability are higher than in the general population,\(^3\) the majority...
of infants have normal development on standardised developmental testing. Earlier assessment and identification of infants at the greatest risk will not only redirect resources where they are likely to have maximal benefit, but also minimise the ongoing burden of follow-up for infants that are well.

There is a need for a national consensus to support quality, effective, equitable and adequately resourced practice. This should include the use of well-researched early assessment tools such as GMA, targeted follow-up and intervention for infants most at risk and a community-based, family- and whānau-centred approach, with the aim to optimise the functional outcomes and well-being of vulnerable infants.

Authors’ declaration of authorship contribution

We declare that all named authors demonstrated roles and responsibilities as defined by the International Committee of Medical Journal Editors.
Competing interests:
Nil.

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