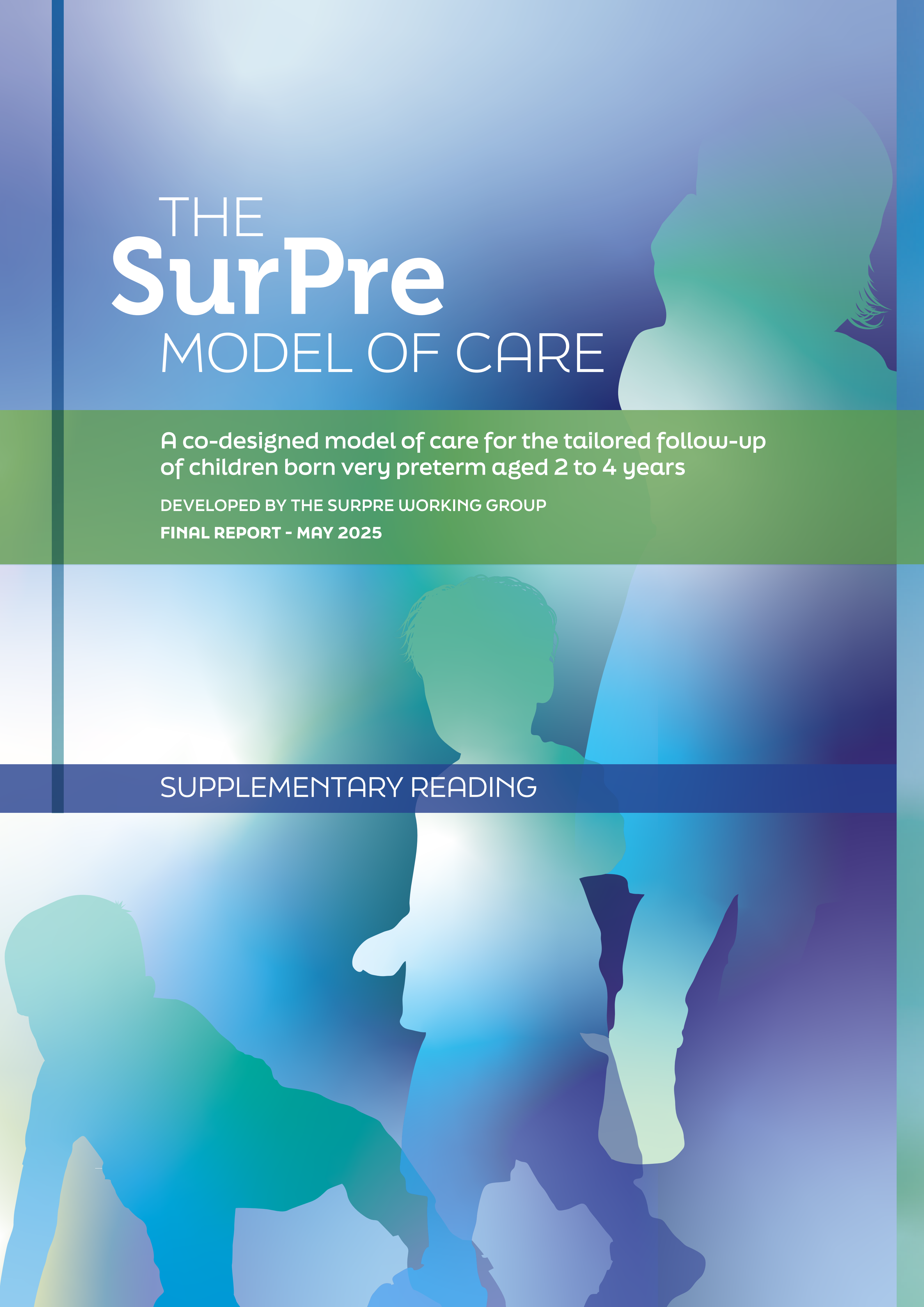

THE
SurPre
MODEL OF CARE

A co-designed model of care for the tailored follow-up of children born very preterm aged 2 to 4 years

DEVELOPED BY THE SURPRE WORKING GROUP

FINAL REPORT - MAY 2025

SUPPLEMENTARY READING

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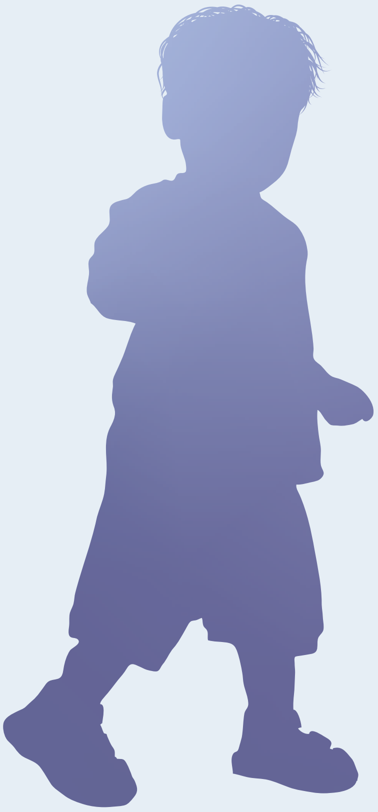


Literature review

Introduction

The aim of this literature review was to identify existing developmental follow-up policies and programs for children born very preterm (VPT) or with very low birthweight (VLBW) and to examine their guiding principles and recommendations with particular attention to the considerations of the Working Group. Key areas of focus included frequency and age of follow-up, strategies for addressing areas of developmental concern, the feasibility for health services implementation, and the diverse circumstances of families. Online content and the peer-reviewed literature were searched on databases using keywords, with a focus on the age range of 2-4 years.

Developmental follow-up programs

Documented follow-up programs for VPT infants are available in many regions including Australia, New Zealand, Canada, Taiwan, Japan, the United States, and Europe. Australia has a joint initiative with New Zealand called the Australian New Zealand Neonatal Network (ANZNN) which collates information, including 2-year outcome data, on children born extremely preterm. All programs have eligibility criteria, most often based according to gestational age and/or birthweight. Some programs consider risk factors such as length of time in the Neonatal Intensive Care Unit (NICU). Developmental follow-up programs most commonly monitor children until they are 2 to 3 years of age, with some programs offering follow-up beyond this age, often linked to school-entry. For example, the Neonatal Follow-Up Clinic in Tasmania, Australia, offers follow-up until 4.5 years of age, whereas a follow-up program in Western Australia gives the option to continue until 5 years of age. At the Neonatal Unit Flinders Medical Centre in South Australia, follow-up extends to 8 years. In Germany, Switzerland and Japan, programs generally continue until the children are 5 to 6 years old.

Most monitoring occurs across various developmental domains including general cognition, language and motor skills, and behaviour. However, information is lacking on the specific tests recommended, and how results may influence further monitoring or access to early intervention services. A detailed description of these programs is presented in Table 1a and 1b.

TABLE 1A. NATIONAL FOLLOW-UP PROGRAMS

NAME	COUNTRY/ REGION	ELIGIBILITY	DURATION/SCHEDULE	NOTES
Neonatal Unit Flinders Medical Centre	AUS, SOUTH AUSTRALIA	Gestation: <32 weeks; Weight: <1500g; Other risks: Term babies with hypoxic ischaemic encephalopathy	Until age 8 years if EPT and ELBW; no detail on schedule.	
Government of Western Australia Neonatal Follow-up Program	AUS, WESTERN AUSTRALIA	Gestation: <32 weeks; Weight: <1500g; Other risks: Major surgery, seizures or fits, serious illnesses	Regular until 12 months; option at 24 months and up to 5 years	Parents receive questionnaire 4 weeks prior to appt; Regular rural centre visits by paediatric team
Tasmania Government Neonatal Follow-up Clinic	AUS, TASMANIA	Gestation: <32 weeks; Weight: <1500g Other risks: Specific medical conditions	8 months, 12 months; 2 years, 3 years, and 4.5 years corrected age	Multidisciplinary team and individually tailored

TABLE 1B. INTERNATIONAL FOLLOW-UP PROGRAMS

NAME	COUNTRY/ REGION	ELIGIBILITY	DURATION/SCHEDULE	NOTES
University of Maryland, Children's Hospital NICU Follow-up Program	USA, MARYLAND	Gestation: <37 weeks; Weight: <1500g Other risks: Difficult newborn period, genetic condition	Every 6 months until age 3 years	Unclear what developmental domains they cover
Nationwide Children's Hospital	USA, PHILADELPHIA	Gestation: <37 weeks; Other risks: Complex medical conditions	3 months; 6 months, 12 months, 18 months; options up to 5 years	
Nationwide Children's	USA, OHIO	Other risks: Being in the NICU	Regular until age 3 years, no detail on schedule	
Johns Hopkins All Children's Hospital -Neonatal Follow-up Care Program	USA, FLORIDA	Weight: <1500g Other risks: Critically ill	First month after discharge; 4 months; 8 months; 12 months; 18 months; then annually until age 5 years	
UC San Diego Health High-Risk Infant Follow-up Program	USA, SAN DIEGO	Gestation: <34 weeks; Weight: <1500g	Every 6 months until age 2-3 years	
Women & Infants Hospital NICU Follow-up Program	USA, PROVIDENCE	Gestation: <34 weeks; Weight: <1500g Other risks: Any special problems, on oxygen, an apnoea monitor, or pulse oximeter	Until age 7, no detail on schedule	
B.C. Women's Hospital & Health Centre Neonatal Follow-up Program	CANADA, VANCOUVER	Gestation: <25 weeks Birth weight: <800g	4 months, 8 months, 18 months; 3 years and 4.5 years	
The Hospital for Sick Children Neonatal Neurodevelopmental Follow-up Clinic	CANADA, TORONTO	Gestation: <37 weeks; Other risks: Serious medical conditions	4 months, 8 months, 12 months, 18 months; 3 years	
Connecticut Children's Medical Centre Developmental Follow-up Program	USA, CONNECTICUT	Gestation: <32 weeks Birth weight: <1500g Other risks: Medical conditions	Every 6 months until age 3 years	
Boston Children's Hospital NICU Follow-up Program	USA, BOSTON	Gestation: <32 weeks Birth weight: <1500g Other risks: Medical or development conditions	Every 4 to 6 months until age 3 years	
University of Nebraska Medical Center High-risk Infant Follow-up Program (TIPS: Tracking Infant Progress Statewide)	USA, NEBRASKA	Other risks: >72 hours in the NICU	6 months, 16 months; 2 years and 3 years; Options (questionnaire or in-clinic) based on complications	Type of follow-up is based on severity. Those Who had a smoother time in NICU are given a questionnaire, and those whose stay was more complicated are to be seen in-clinic.

TABLE 1B. INTERNATIONAL FOLLOW-UP PROGRAMS (continued)

NAME	COUNTRY/ REGION	ELIGIBILITY	DURATION/SCHEDULE	NOTES
Children's Hospital of Orange County High-Risk Infant Follow-up Clinic	USA, CALIFORNIA	Gestation: <34 weeks; Weight: <1500g Other risks: Difficult birth, illness, severe respiratory distress, heart surgery	Until age 3 years	
Children's Minnesota Intensive Care Follow-up Clinic	USA, MINNESOTA	Gestation: <37 weeks; Other risks: Medical complexities	Until age 5 years	
Columbia University Department of Pediatrics Neonatal Neurodevelopmental Follow-up Program	USA, NEW YORK	Gestation: <32 weeks; Weight: <1250g Other risks: seizures, strokes, meningitis. tracheostomy	Until age 3 years	Multidisciplinary team but does not assess language
Massachusetts General Hospital Newborn Developmental Follow-up Clinic	USA, MASSACHUSETTS	Gestation: <32 weeks; Weight: <1500g Other risks: brain haemorrhage, strokes, opioid exposure	3 months, 7 months, 12 months, 18 months; age 2 years; option to continue until age 3	Multidisciplinary team but does not cater to cognitive domain
Hamilton Health Sciences Neonatal Follow-up Clinic	CANADA, ONTARIO	Gestation: <29 weeks; Weight: <1500g	Until age 3 years	
Boston Children's Hospital NICU Growth and Developmental Support Programs	USA, BOSTON	Gestation: <35 weeks; Weight: <1500g Other risks: Complex medical conditions, genetic diagnoses	Every 6 months until age 3 years	Multidisciplinary team but unclear if they assess language
Newark Beth Israel Medical Centre High-Risk Infant Follow-up Program	USA, NEW JERSEY	Gestation: <37 weeks; Other risks: Developmental delays		
Canadian Premature Babies Foundation Neonatal Follow-up Clinic (NFC)	CANADA	Criteria are based on how early the child was born, weight, and other illnesses in the NICU, differs across Canada	4, 8, 12, 18, and 36 months corrected age; Option into early school age	
United Kingdom Government Healthy Child Program	UNITED KINGDOM	Gestation: <37 weeks	2 and 2.5 years of age	

Policies and guidelines

Age to follow-up

Recommendations from the published literature vary. A recent review reported on the national recommendations and regional policies for VPT infants that exist in 11 European countries.[1] Overwhelmingly, recommendations are to monitor VPT and VLBW children until at least 5 years of age. Some exceptions were Denmark and Belgium whose eligibility criteria were children born at 'less than 28 weeks' and the recommended age to follow-up in Italy, Poland and the UK was 3-4 years[1,2] and 6-7 years in Spain.[3] In Australia, the NHMRC Guideline for Growth, Health, and Developmental Follow-up for Children Born Very Preterm recommends follow-up until 4 to 5 years of age.[4] The Indian National Neonatal Forum Clinical Practice Guidelines recommend follow-up until adolescence would be desirable if not practicable, and that moderate to high-risk infants should be seen at least once a year until age 5.[5] Other recommendations for monitoring high risk infants are until 3 years of age in Canada,[6] 5-7 years of age in Texas,[7] 8 years of age in India[8] and 14 years of age in Spain.[3]

Nature of follow-up

All guidelines cover monitoring in general developmental domains of cognition, language, behaviour, and motor.

In addition, the Indian National Neonatal Forum Clinical Practice Guidelines define three categories of risk (low, moderate and high) and propose different health disciplines to provide specific monitoring depending on risk level.[5] For example, children at low risk are seen by a paediatrician to screen for any developmental delays, whereas children in the high-risk category are evaluated by a multidisciplinary team including speech and occupational therapists.

The policy of the American Academy of Paediatrics recommends that long-term follow-up for preterm infants includes collaboration with a range of health professionals to provide multidisciplinary care.[9] Involvement of multidisciplinary teams is relatively common in follow-up programs, and may include psychologists, physiotherapists, speech or language pathologists, occupational therapists, and a coordinator from the program.[10]

The European Standards of Care for Newborn Health[11] provide guidance on when follow-up should occur for each developmental domain. For example, they recommend neuromotor follow-up into school age and cognitive follow-up during the transition to secondary school. In the UK, the National Institute for Health and Care Excellence (NICE), recommends in-person developmental assessments at 2 and 4 years of age.[12] At 4 years of age, parents complete a questionnaire about their child's behaviour, which is then discussed during the assessment. The in-person assessment involves administering an IQ test, conducting a motor assessment if the child has been diagnosed with cerebral palsy, and confirming that the child has been offered orthoptic vision screening (NICE, 2017, section 1.3.13). After the 4-year assessment, they recommend that parents and the neonatal consultant receive a summary of the child's strengths and weaknesses, as well as any ongoing developmental concerns (NICE, 2017, section 1.3.14).

Other recommendations to the nature and frequency of developmental follow-up include this to be at 3-monthly intervals if scores of measures of developmental delay (eg. Bayley Scales) are well below expectations for their age,[8] yearly wellbeing checks at 3-5 years of age at a primary care facility, followed by a cognitive, behavioural and emotional evaluation at 5 years of age at a hospital, plus a questionnaire on academic performance every year from 4 years onwards.[3]

Further, there are obvious resource considerations in the implementation of these recommendations[13] which are not included in this literature review.

Guiding principles for follow-up

Guiding principles are the foundational components that underpin the quality and delivery of health care, and this review also describes any such elements as published in the literature.

One study developed a set of quality-of-care indicators for the follow-up of VLBW children.[14] These indicators are designed to measure the quality of care in follow-up. They were derived from the literature and included if they measured aspects of care quality, such as positive outcomes from interventions.[14] These were presented to an expert panel of paediatricians and health professionals. The panel recommended 70 indicators in follow-up in the areas of hearing, vision, language, behavioural and psychosocial skills. The panel acknowledged that while it would be preferable for certain disciplines to assess performance in specific domains, there needed to be some flexibility and special considerations given to regional or rural settings, where there may be no access to certain health professionals.[14] Further to this, other studies have had some success with specialist telehealth consultations during their appointment with the family's regular clinician.[15,16]

One study reviewed current models of follow-up care and recommended four key considerations in the design of a family-centred clinical follow-up service.[17] These are; 1) Follow-up care should be responsive and reflect a family's needs and values, 2) Health professionals should outline clear goals of the child and the purpose of appointments, and should be communicated appropriately to parents about the reasoning for referrals and services, and are aligned with their values, 3) Offering other services that are not face-to-face, to increase participation and reduce barriers to accessibility, and 4) Follow-up programs should use similar outcome measures for assessments so comparisons can be made across other services. Along the same lines, a Canadian follow-up program redesigned its structure and proposed three principles for follow-up, two of which are only relevant to this model of care.[18] The two principles included 1) The surveillance for common disabilities to ensure early intervention, and 2) Follow-up should be based on touchpoints (e.g. transition to school), rather than on domains, as this can be costly, time-intensive, and tiring for the child.[18] Other researchers have noted that this approach may be more beneficial as they directly respond to the developmental needs of the child as they make progress over time, rather than appointments being based on age.[10]

The publishing literature have suggested applying frameworks to follow-up to help ensure high quality developmental monitoring. One of the frameworks is called the life course health development. This framework has been applied to other health conditions, such as heart disease, and is used to explain how a person's life changes across the lifespan.[10] Researchers have adapted this framework in the context of follow-up for preterm infants.[10] The framework contains a set of principles to improve follow-up care and improve health outcomes for children beyond 2 years of age by integrating health, education, and social systems. Some of these principles involve family centred care and goal-setting, appointments arranged when needed, a focus on key developmental periods, and a strength-based approach.

Other researchers have developed a framework that examines risks based on how much more common a disability is in preterm children, compared to the risk in the general paediatric population.[9] They have used data from the last 20 years on how to assess the degree of risk for this framework, and have formulated three different categories.[9] The first category, 'very high risk', includes conditions that have at least a 10 times higher risk compared to the general paediatric population; the second category, 'high risk', includes conditions that are 5 to 9.9 times higher risk; and 'moderate-to-low risk' includes conditions that are 1.1 to 4.9 times higher risk. The purpose of this framework is to make it easier for paediatricians to decide the appropriate level of follow-up for each child.[9]

Screening tools for parents

Use of screening tools in developmental follow-up was examined in a Danish study of 42 children born extremely preterm (EP) at 5 years of age, where parents used a screening tool to assess their children for fine motor problems.[19] The study found that parent-report of fine motor problems correlated with those identified in formal assessments.[19] The researchers proposed that it may be necessary to implement parent reporting screening tools, even for children who may not have a diagnosis as a way of monitoring, and to replace some of the formal assessments as they can be time-consuming. There are many screening tools to choose from and while some guidelines include specific recommendations, the choice is usually left to individual health professionals based on the local availability of the tool and clinician training and expertise.[13] Incorporating parent-reported screening tools can assist with the follow-up of children in rural areas, as studies have showed those living in rural areas are less likely to attend follow-up due to costs and having to take time off work.[1,17,20]

Health professionals perspectives on follow-up

A survey was administered to paediatricians and Child Developmental services in New Zealand to see how they were managing follow-up of preterm infants. Out of 34 responses, the most common response for improving follow-up was the need for more funding and access to resources.[20] The majority of paediatricians in the survey stated if a child had done well in previous assessments, they were less likely to be followed-up, with limited resources being the main cause.[20] Regarding follow-up difficulties, 44% reported an inability to keep up with the demand, a lack of health professionals not trained in assessments, not enough time to administer these assessments, and shortages of certain specialists.[20] One of the District Health Boards stated they could only see children once a delay was identified, and the process would be better if there were more resources provided for early intervention. In the United States, a survey was completed by 10 neonatologists, with 7% reporting a limited number of follow-up programs. Over 60% reported a lack of qualified health professionals and financial resources as being the most common reasons for not having a follow-up program[21]. In Canada, healthcare providers discussed some of the barriers that impacted their ability to provide care. Some described the healthcare system being under stress, due to staff shortages, cutbacks, wait lists, and scheduling restrictions.[22] Another barrier was that follow-up services were viewed as an intermediary service. Organisations and policymakers showed less interest in these services because they are neither emergency services nor paediatrics. Since the focus is on prevention, it may be difficult for organizations to recognize the long-term importance of these services.[22]

Follow-up attendance rates

In Australia, the Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm states that around 15% of eligible children are not involved in follow-up during the toddler period.[4] Furthermore, over 60% of children born VP do not have access to structured follow-up care.[4] A study in Europe that involved over 3,000 children found 90.3% had been involved in such a program at some stage. However, at age 5, only 27.3% were still engaged with a program.[1] The same study reported that countries with national or regional policies showed the highest level of family engagement in follow-up. In a study of 1,737 children across 4 regions in the United Kingdom and Portugal, researchers found only 54.2% were followed-up at 2 years of age.[23] They also found mothers who were younger, or foreign-born, were less likely to attend follow-up. In the United States, directors of 183 follow-up clinics reported 50% to 80% attendance rate, but dropout rates increased with follow-up appointments overtime.[9]

Uptake of follow-up programs

(PARENTAL PERSPECTIVES)

Research shows that while developmental follow-up is important, several factors influence parents' willingness and ability to attend appointments. These chiefly relate to whether parents have any concerns for their child and their level of understanding of the purpose of these appointments.

Table 2 summarises parents' views on barriers and facilitators relating to parental uptake of child developmental monitoring.

TABLE 2. **BARRIERS AND FACILITATORS RELATING TO PARENTAL UPTAKE OF CHILD DEVELOPMENTAL MONITORING.**

THEMES	BARRIERS	FACILITATORS	POSSIBLE SOLUTIONS
Knowledge	Parents view follow-up as not important; No concern for child's development, negative view of follow-up services[11, 17]	Better understanding the need to monitor even when child is progressing well[17, 32]	Educate parents on the purpose of follow-up[17]
	Parents unaware of the types of services available[11, 16]	Health professional to communicate and provide referrals to parents/families[10, 11, 16,]	Advertisements (e.g. leaflets at doctor's offices)[10]
	Lack of training amongst health professionals in regional and rural areas[9, 16, 17]	Health professional training in prematurity[16]	Local health professionals liaising with other experts over telehealth[32, 33]
Accessibility of services	Time commitment; Limited appointment times[17] Living in regional or rural areas[9, 16, 17] Relying on public transport[14, 17] Associated costs (e.g. parking, taking time off work)[10, 14, 15] Congestion at facility[17]	Flexible appointment times[10, 11, 31] More specialists located in regional and rural areas, screening tools for parents[16, 17, 34]	Use of telehealth services to access specialists in metropolitan areas[9] Mobile teams to set up work in regional area for a period[13]
Communication	Poor communication; low parental health literacy[31]	Effective and clear communication[31] Expecting news at appointment[14] Child's positive characteristic are highlighted in feedback[35] Written summary of feedback[31] Health professional reassuring parents about child's development; giving support to parents[11, 14, 31]	Simple language that is at an 8th grade level of reading; teach-back communication with healthcare providers[36]
	Lack of information sharing amongst health professionals and continuity of care[11] No referrals given to parents; Burden on families to organise this themselves[10, 11] Inconsistencies of services offered across health districts[9]	Records shared across health services[10] Care coordination between providers[11] Assistance with navigating the system[14] Organising appropriate referrals for families and their specific needs[9, 10]	None reported
Type of care	Standard care[8] Services potentially losing funding if child sees another specialist that may be a better fit[9]	Family centred care[8, 10, 14, 16] Individualised approach[17]	None reported
Social factors	Young mothers[37] Culturally and linguistically diverse[38, 39], Foreign born[37], language barriers[40, 41]	Peer-to-peer support for mothers[17] Culturally safe delivery of services and awareness of cultural factors[41, 42]	Training in cultural competency and responsiveness[41, 42]

Special considerations

Parental mental health

It is important to acknowledge parents' mental health. Parents have reported the need for long-term emotional support, and local peer support groups in regional and rural areas.[13,39,40] Barriers to seeking support include insufficient referrals and a lack of awareness about available resources.[28] As an element of preterm care, the World Health Organisation has recommended having peer support groups for parents' post-discharge follow-up.[25]

Aboriginal and Torres Strait Islanders

Aboriginal and Torres Strait Islander infants are less likely to be engaged with maternal and child health services compared to non-Indigenous infants.[38,41] Low healthcare service engagement among Indigenous Australians has been linked to language barriers, and past negative experiences involving culturally inappropriate or unsafe delivery.[37,38] This is concerning because preterm birth rates are doubled in the Aboriginal population,[38] and studies have shown children have worse health and development outcomes compared to non-Indigenous children.[41,42] Indigenous infants are also less likely to have access to specialists (e.g. paediatricians), and instead, rely on hospitals.[41] In a review of Aboriginal child healthcare services in remote areas, it was reported there was a lack of healthcare professionals, and there was limited experience and expertise among those available.[42] Additionally, when looking at service quality to Aboriginal infants, it was found some staff accepted anaemia and growth faltering as a 'normal' part of development in this population, rather than treating it.[37] Indigenous Australians' access to health services is still underreported. One review showed there is currently a lack of research on service usage and continuity of care among Aboriginal families in the first 1000 days of an infant's life.[38] Since Aboriginal and Torres Strait Islander children have poorer health outcomes, and have added challenges, like living in rural areas,[42] this limits their access to care, and even more so if culturally safe practices are not in place.

Culturally and linguistically diverse backgrounds

Evidence shows that those of CALD backgrounds tend to face barriers in receiving appropriate care.[35,36] Barriers include difficulty with communication, having lower levels of health literacy, and a lack of transportation.[35] Studies have found that children from CALD backgrounds who had low birth weight, or were born prematurely, had more chronic diseases and language delays, compared to non-CALD children.[35,43] When accessing mental health services among CALD women, it was suggested that policies should extend from cultural competence to cultural responsiveness.[44] Cultural responsiveness aims to consider all aspects of one's identity, to create a meaningful and individualised approach.[44] The biases of health professionals can hinder cultural responsiveness, with one study recommending that healthcare professionals need to acknowledge their biases, as this could reduce racial and ethnic inequities in care within programs for high-risk infants.[17]

Health literacy

One study highlighted health literacy as an important principle for follow-up in high-risk infants.[17] Health literacy is about providing information that is clear, and in a family's preferred language.[17] A study investigated health literacy in 137 parents of very preterm infants, and found one third had low health literacy levels, with 12% of those having a college degree.[33] Health literacy approaches include simple language that is at an 8th grade level of reading, teach-back communication with healthcare providers, and reinforcing information.[33] Parents and caregivers were asked for feedback about what they would like in follow-up, and they also wanted improved communication from health professionals.[24]

Regional and rural areas

The majority of follow-up clinics are located in urban areas, and when considering geographical remoteness, studies have found those living in regional or rural areas have reduced access to healthcare services due to costs of travel, and potentially having to take time off work.[9,17,37] In the United States, a survey found more than half of the NICU programs did not have a plan for addressing the needs of those living in rural areas.[9] Studies have found greater distance from follow-up services was associated with lower access, and being more remote is associated with worse maternal and child health outcomes.[38,45] Children living in rural and/or remote areas tend not to see paediatric subspecialists and instead rely on emergency services.[46,47] Addressing these disparities is crucial in reducing inappropriate use of emergency services, as well as ensuring services are equitable across rural and remote areas.[22]

Telehealth

A solution for addressing access to follow-up in remote communities, is the use of telehealth services.[14,48] A study assessed 43 follow-up programs for high-risk infants on their use of telehealth services, and it was found that telehealth was a good replacement for face-to-face visits.[49] It increased family-centredness, and decreased costs and transportation, which are common barriers for parents when accessing follow-up services.[49] Whilst there are particular instances where telehealth may not be appropriate (e.g. some assessments needing to be done in person), when studies have assessed children via telehealth for autism, remote clinicians have accurately diagnosed participants over 80% of the time.[30,31] Parents involved in these telehealth assessments, reported feeling satisfied with the process, as it was convenient, and saved them an average of four hours of travel time.[30] Another study illustrated this when assessing musculoskeletal conditions via telehealth. In-person and telehealth delivery were in agreeance over 80% of the time when it came to recommendations about management.[16]

Methodology and summary of results and activities

The project received ethics approval from The Royal Children's Hospital Human Research Ethics Committee (HREC/88935/RCHM-2022). All participants consented via implied consent through attendance in group or individual consultations.

Stakeholder consultations

Purpose

The stakeholder consultations aimed to collect the perspectives and experiences of families and health care professionals on current follow-up care processes for children born very preterm. Participants were asked about factors that promote effective follow-up, barriers to it and key components to include in a follow-up care model. The insight gathered, along with the literature review, provided essential context for the Working Group's co-design phase.

Recruitment

To ensure a diverse range of perspectives, we developed an online expression of interest form, which was widely distributed through national networks, professional and family support groups, and contacts from the investigator team, Steering Committee and Advisory Committee. Our goal was to have at least 50% of participants be individuals with lived experience, alongside 50% community health professionals or those experienced in follow-up care of very preterm children.

Focus group and interview procedures

Focus groups for individuals with lived experience were conducted separately from those for health professionals to ensure participants felt comfortable in sharing their experiences and perspectives. We aimed for each focus group to consist of a minimum of five participants and a maximum of 10 participants. Focus groups with people with lived experience were facilitated by co-chair Cruz and with support from the two research team members. Focus groups with health professionals were facilitated by co-chair Roberts, also supported by two research team members.

Focus group scheduling was flexible to accommodate all participants. Discussion topics were shared in advance (see below). Sessions were held online via Zoom, recorded for data capture and subsequently transcribed verbatim for analysis.

Discussion guide

STAKEHOLDER CONSULTATIONS WITH PEOPLE WITH LIVED EXPERIENCE:

1. **In your experience, what are the things that went well with the follow-up care of your child/children?**
   a. Positive experiences – how it helped establish ongoing care/therapy arrangements
   b. Logistics
   c. Health professionals involved and if developmental concerns addressed.
   d. Clear purpose of follow-up

2. **In your experience, what are some of the things that didn't go so well with the follow-up care of your child/children?**
   a. Challenges/frustrations
   b. Any therapy or medical input you felt was needed but not provided
   c. Understanding of the types of developmental tests and roles of the different health professionals
   d. Barriers to attending appointments.
   e. Logistics - which aspects made it harder
   f. Length of follow-up period and who initiated discontinuing it.

3. **If you were to design a follow-up program for children born very preterm for your family, what would it look like and what would be in it?**
   a. Elements/ingredients/components – tests, education about different tests and roles of health professionals
   b. Professionals involved and when.
   c. Inclusive of culturally diverse, Indigenous populations and people with non-English speaking backgrounds
   d. Logistics
      i. setting - hospital vs community vs less formal (playgroups etc)
      ii. how appointments made, getting to appointments
      iii. in person vs online

STAKEHOLDER CONSULTATIONS WITH HEALTH PROFESSIONALS

1. **In your experience, what are the things that enable good follow-up care of children born very preterm?**
   a. Enablers/facilitators
   b. Logistics
   c. Health professionals involved.

2. **In your experience, what are the things that make follow-up care of children born very preterm challenging or suboptimal?**
   a. Challenges/barriers
   b. Logistics
   c. Health service issues.

3. **If you were to design a follow-up program for children born very preterm, what would it look like?**
   a. Elements/ingredients/components e.g. assessments, area of development targeted.
   b. Professionals involved and timing.
   c. Inclusivity of culturally diverse, Indigenous populations and people with non-English speaking backgrounds
   d. Logistics
      i. setting - hospital vs community vs less formal (playgroups etc)
      ii. how appointments made, attendance of families at appointments etc.
      iii. in person vs online

Participation

There were 73 people who expressed interest in participating in the focus groups: 53 individuals with lived experience (parents of children born VPT) and 20 community health professionals. 22 parents (1 father and 21 mothers) and 15 community health professionals were able to participate at the scheduled times. The community health professionals included six physiotherapists, three paediatricians, three psychologists, one speech and language pathologist, one dietician, and one nurse. Of the 37 total participants, 27 lived in metropolitan centres and 10 lived regionally, rurally or remotely. Participants represented all states and territories of Australia, except for Tasmania: Victoria (14), NSW (7), Queensland (6), Western Australia (6), Northern Territory (2), Australian Capital Territory (1), South Australia (1). There were seven focus groups ranging in size from 4-8 participants and two individual interviews.

Qualitative data analysis

We employed inductive content analysis to generate practical suggestions for the model of care.[50] NViVO 12.0plus software (QSR International, Melbourne, Australia) facilitated this analysis. After familiarisation with the data, two researchers independently completed coding in two rounds. The first round identified major themes and developed a preliminary coding framework, while the second round involved a detailed line by line process to produce subcategories, resulting in a refined coding schema.

Findings

The comprehensive results of the qualitative data analysis of the focus group transcripts are outside the scope of this report. However, a summary of key topics and points related to effective follow-up care is provided in Table 3.

TABLE 3. SUMMARY OF TOPICS RAISED IN FOCUS GROUPS WITH PARENTS OF CHILDREN BORN VERY PRETERM AND COMMUNITY HEALTH PROFESSIONALS.

TOPICS	DETAILS
Continuity and consistency of care	Parents emphasised the importance of consistent care across different centres to ensure they don't feel disadvantaged based on their child's place of birth. Maintaining continuity when feasible, reduces stress and enhances efficiency, and health professionals become familiar with the child's needs. Flexibility in appointment scheduling is also highly valued.
One main point of contact for families	Both parents and health professionals noted that having a single point of contact, such a nurse coordinator or clinic coordinator, significantly aids family engagement and reduces family stress.
Support networks for families	Many parents shared that attending regular parent groups and playgroups can be challenging, especially when their children are considerably delayed compared with peers. Playgroups and support networks for families with preterm children play a crucial role in alleviating anxiety.
Education for families to empower them	Parents and health professionals highlighted the necessity of addressing health literacy by educating families early about what to expect and why follow-up is important. A clear plan or roadmap would help parents to feel more in control and reduce anxiety.
Context and location of care setting	Many parents reported that returning to the hospital where their child spent weeks or months as a baby can be traumatic for follow-up appointments Additionally, both parents and health professionals indicated that travel to a tertiary centre can be problematic for some families due to financial restraints, logistical challenges, or lack of transportation. Considering local and community locations for follow-up is especially important for those in regional, rural and remote locations.
Upskilling and support for local health professionals	Parents expressed the need for local health professionals to receive additional training in managing children born very preterm. Health professionals also stressed the importance of embedding skilled clinicians in the community, including GPs, nurses, and allied health professionals, particularly for families living rurally and remotely. They suggested utilising telehealth services or hybrid models where local health professionals can collaborate with tertiary centres through telehealth. Furthermore, both parents and health professionals felt that the child's green/blue/red book can provide additional information on typical developmental progress.
Systems for efficient tracking of children and families	Health professionals indicated that reliable databases and tracking systems are essential to ensure efficient follow-up and prevent children from being overlooked. Families also need support to remain engaged in the follow-up process.
Mental health support	Many parents highlighted a clear need for mental health support for families navigating the challenges of caring for very preterm children.
Pragmatics of services available	Health professionals noted that multidisciplinary care is necessary for children born very preterm, but the availability of specific services often varies based on the site and its resources.

Working Group activities

Meetings

The Working Group met regularly via Zoom from October 2023 to September 2024. Co-chaired sessions included information sharing, recaps of previous meetings, discussions, and decision-making. Initial meetings focused on establishing context, defining terms of reference and agreeing on the groups' purpose and goals. Subsequent decision-making meetings followed a structured roadmap with specific topics designated to each session. The final meeting focused on integrating insights and tailoring the Model of Care to meet the unique needs of individual children and families. During the online meetings, participants were divided into smaller breakout rooms to discuss the designated topic, followed by a full group discussion. Meetings were recorded to allow those who could not attend to catch up on the presentations and discussions.

MEETING ATTENDANCE

See Table 4 for details of numbers in attendance at each.

TABLE 4. ATTENDANCE AT WORKING GROUP MEETINGS

DATE OF MEETING	PEOPLE WITH LIVED EXPERIENCE	COMMUNITY HEALTH PROFESSIONALS	NEONATAL PROFESSIONALS	TOTAL NUMBER
28-11-23	8	2	7	17
22-02-24	10	2	7	19
20-03-24	8	2	1	11
18-04-24	11	2	5	18
23-05-24	9	1	5	15
18-07-24	10	3	5	18
11-09-24	9	2	2	13

Co-design evaluation

At the conclusion of each zoom meeting, attendees were encouraged to complete a short online survey to assess how well the meeting reflected co-design practices.

The aggregated results from this survey are presented in Table 5. Across all sessions, more than 90% of participants agreed or strongly agreed they felt included, supported, able to participate, and able to share new ideas and that the meetings worked towards clear goals. Over 95% expressed some level of satisfaction with the meetings, while 85% felt very or extremely engaged during the meetings.

TABLE 5. EVALUATION OF CO-DESIGN OF THE WORKING GROUP MEETINGS: 53 RESPONSES FROM ALL MEETINGS COMBINED

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE
I felt included in the session	0 (0%)	1 (1.9%)	3 (5.7%)	11 (20.8%)	38 (71.7%)
I felt I had enough support to contribute if/when I wanted to	0 (0%)	1 (1.9%)	1 (1.9%)	15 (28.8%)	35 (67.3%)
I felt like I could participate if/when I wanted to	0 (0%)	1 (1.9%)	3 (5.7%)	13 (24.5%)	36 (67.9%)
I felt like the session was responsive and open to new ideas.	1 (1.9%)	0 (0%)	1 (1.9%)	13 (24.5%)	38 (71.7%)
I felt like the session worked towards and achieved clear objectives	0 (0%)	2 (3.8%)	3 (5.7%)	21 (39.6%)	27 (50.9%)
	VERY DISSATISFIED	**DISSATISFIED**	**NEUTRAL**	**SOMEWHAT SATISFIED**	**VERY SATISFIED**
Overall, how satisfied were you with the session today?	0 (0.0%)	0 (0.0%)	2 (3.8%)	11 (21.2%)	39 (75.0%)
	NOT AT ALL ENGAGED	**SLIGHTLY ENGAGED**	**MODERATELY ENGAGED**	**VERY ENGAGED**	**EXTREMELY ENGAGED**
Overall, how engaged did you feel during the session today?	0 (0%)	1 (1.9%)	7 (13.5%)	37 (71.2%)	7 (13.5%)

Consensus polling overview

After each meeting, items requiring consensus were submitted to an online vote via REDCap, allowing all members to document their views, regardless of attendance. An item was considered agreed upon if ≥75% of members voted in favour. By the end of all sessions, the Working Group reached consensus on three key outcomes: 1) a draft model of care, 2) principles integrated into the model, and 3) considerations for tailoring the model to meet the needs of individual children and their families.

Below is a summary of the consensus reached through these polls across all sessions. The complete results of the polls and a summary of comments from Working Group members are presented at the end of this section.

LEVELS OF FOLLOW-UP

There was a consensus to establish three levels of developmental follow-up based on the likelihood of issues arising in any developmental domain. The preferred terms for these levels were "lower risk," "moderate risk," and "higher risk."

DOMAINS OF INTEREST

The Working Group reviewed common developmental domains monitored for children born very preterm including motor skills, cognition, language, behaviour, and education. It was agreed to remove "education" as a targeted neurodevelopmental domain for children aged 2-4 years, as this is not age appropriate. For each of the remaining domains, three levels of risk were established, along with agreed-upon follow-up requirements.

Motor domain

Consensus was achieved for the motor skills domain:

Lower Risk: Parents should complete a motor skills screening questionnaire every six months.

Moderate Risk: Children should have their motor skills assessed in person by a clinician once a year, with an additional questionnaire completed by parents once in between.

Higher Risk: Children should have their motor skills assessed in person by a clinician every six months.

Cognition and language domains

Consensus was reached on the following for cognition and language:

Lower Risk: Screening of cognition and language should occur twice a year using a questionnaire completed by parents, with support from a health professional if needed.

Moderate Risk: Formal assessment of cognition and language by a health professional should be done once a year (in-person or via telehealth), with a questionnaire completed by parents once in between.

Higher Risk: Language assessment by a health professional (in-person or via telehealth) should occur every year. In the six months between assessments, focus should be on specific areas of concern (e.g., attention, impulse control, working memory, comprehension, articulation) since certain formal tools should not be administered more than once a year according to their publishers' guidelines.

Behaviour domain

Consensus was reached for the behaviour domain as follows:

Lower Risk: Children should be screened twice a year using a brief parent-reported behaviour questionnaire, such as the Strengths and Difficulties Questionnaire.

Moderate Risk: Children should undergo an in-depth evaluation once a year using a comprehensive behaviour questionnaire, such as the Child Behavior Checklist (including parent reports and additional informants if appropriate), and be screened with a brief behaviour questionnaire once in between.

Higher Risk: Children should have in-depth evaluations twice a year using a comprehensive behaviour questionnaire like the Child Behavior Checklist (including parent reports and additional informants if appropriate).

Screening/assessment tools

There was agreement that clinicians and clinics should refer to the 'Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm' when selecting assessments and screening tools for all domains. It was agreed that screening measures should be provided to families with two options for completion: 1) families can complete them independently, or 2) they can complete it with the support of a health professional.

OTHER CONSIDERATIONS

There was consensus that health professionals should provide feedback to families and discuss plans for the next six months. Parents' perception of their child's strengths and challenges will be discussed during the screening and assessment process. If appropriate, a child may be reclassified to another risk level based on the screening results and subsequent discussion between the health professional and family.

SCREENING SCHEDULE

A questionnaire to be sent to families, followed by a telephone appointment. Families can opt to complete the screening with the assistance of a health professional. There may be further focused screening or diagnosis in identified areas of concern. After the screening, the health professional will discuss management strategies for the next six months with the family, including any necessary reclassification.

ASSESSMENT SCHEDULE

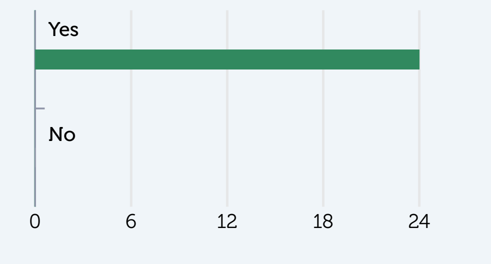
An in-person appointment will be arranged for assessment, which will be conducted by a qualified health professional. Following the assessment, the health professional will discuss management strategies for the next six months with the family, along with any necessary reclassification.

Details from consensus polls

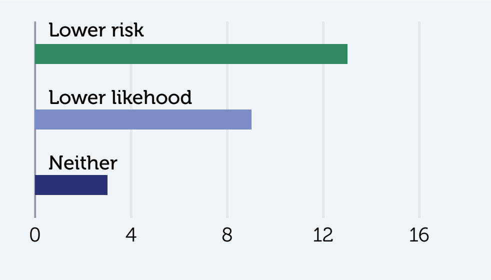
POLL ONE: MARCH 2024
TERMINOLOGY AND OUTCOME DOMAINS

25 participants: 13 parents (52%),
4 community health professionals (16%),
8 neonatal managers or follow-up professionals (32%)

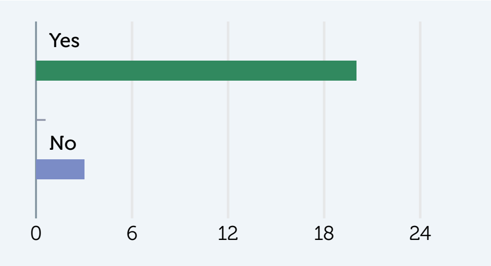
QUESTION 1. **Regarding the proposed levels of developmental follow-up and their descriptors, do you agree with keeping 3 levels of developmental follow-up based on the likelihood for problems in any developmental domain?**



QUESTION 2. **Regarding the proposed levels of developmental follow-up and their descriptors, which of the following suggestions do you think are best to describe the likelihood of a child's level of vulnerability in any developmental domain.**



QUESTION 3. **Do you support the suggestion to drop "education" as one of the targeted neurodevelopmental domains for children aged 2-4 years, considering that skills in this domain are yet to emerge at this age and potential vulnerabilities can be addressed through cognition and language domains?**



Summary of comments from Working Group members in poll one

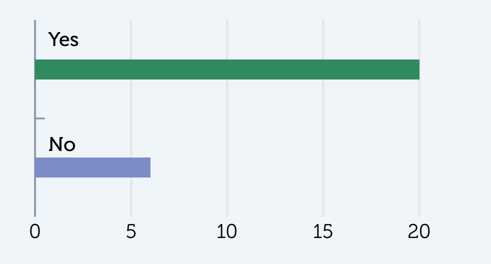
Terminology. Although risk can have negative connotations for some families, it is a well understood phrase and it is best to keep terminology simple and clear.

Education. School readiness to be considered rather than education and can be captured through other domains.

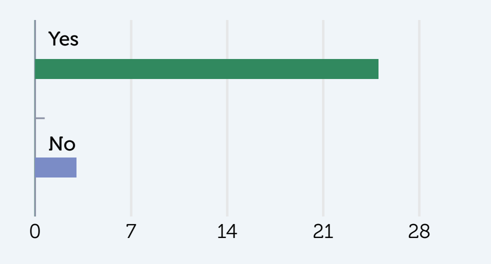
POLL TWO: APRIL 2024
MOTOR SKILLS

27 participants: 13 parents (48.1%), 3 community health professionals (11.1%), 11 neonatal managers or follow-up professionals (40.7%).

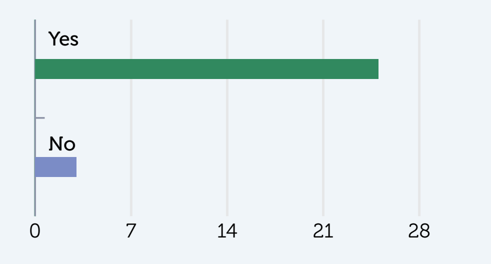
QUESTION 1. Do you agree that children in Pathway 1 (lower risk) should have their motor skills screened using a questionnaire completed by their parents every 6 months (i.e. twice yearly)?



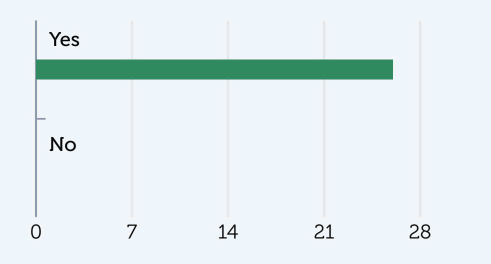
QUESTION 2. Do you agree that children in Pathway 2 (moderate risk) should have their motor skills assessed in person by a clinician once yearly and screened using a questionnaire completed by their parents once in between?



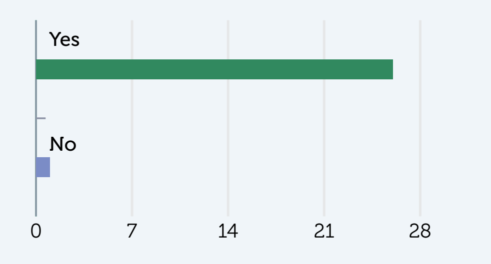
QUESTION 3. Do you agree that children in Pathway 3 (i.e. higher risk) should have their motor skills assessed in person by a clinician every 6 months (i.e. twice yearly)?



QUESTION 4. Do you agree that clinicians/ clinics should refer to the 'Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm' when considering motor assessments and screening tools?



QUESTION 5. Do you agree that children can move between pathways based on the level of risk identified through their testing at the discretion of the clinician, parent or carer?



Summary of comments from Working Group members in poll two

Some families may require support from a health professional to complete the screening questionnaire, either in-person or over the telephone.

Children who are at higher risk may require more frequent assessment based on findings or may require fast tracking if parents are concerned.

Any movement of a child between risk categories/level of follow-up should be based on discussion between the parents and relevant health professional.

POLL THREE: MAY 2024
SCREENING AND COGNITION AND LANGUAGE

24 participants: 12 parents (50%),
3 community health professionals (12.5%),
9 neonatal managers or follow-up
professionals (37.5%).

QUESTION 1. Screening. At the meeting on May 23rd, we provided further details for the screening process for children in Pathway 1 (lower risk) for all domains. We propose that: Screening measure(s) will be sent to the families.

OPTION 1: Families can complete it themselves.

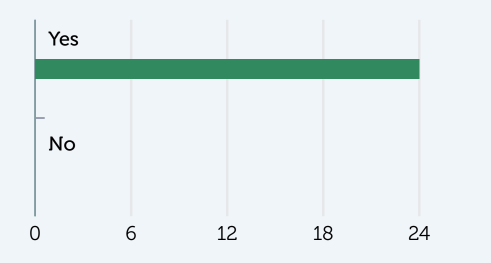
OPTION 2: Families can complete it with the support of a health professional.

Feedback to be given back to families by the health professionals, and plans for the next 6 months discussed.

Parents perception of their child's strengths and challenges will be discussed.

If appropriate, a child may move to another risk level based on the results of the screening and consequent discussion between the health professional and family.

Do you agree with this proposal for screening?

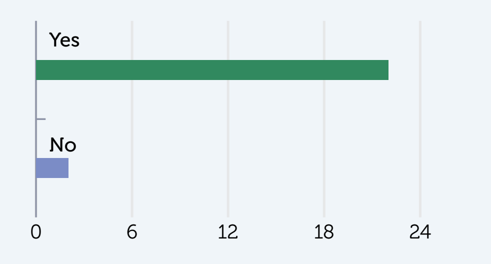


QUESTION 2. Cognition and language. In the meeting we also proposed the following procedure for monitoring cognition and language for children born very preterm when they are 2-4 years of age.

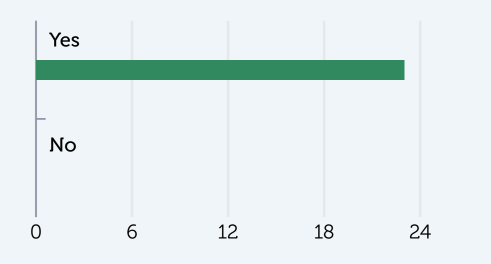
PATHWAY 1 (LOWER RISK): children have twice yearly screening of cognition and language using a screening questionnaire completed by their parents, with the support of a health professional, if needed, every 6 months (i.e. twice yearly).

PATHWAY 2 (MODERATE RISK): children have their cognition and language formally assessed by a health professional once yearly (in-person or via telehealth) and administered a screening questionnaire once in-between.

PATHWAY 3 (HIGHER RISK): children have their cognition and language formally assessed by a health professional (in-person or via telehealth) every 6 months (i.e. twice yearly) Do you agree with this proposed procedure for monitoring cognition and language?



QUESTION 3. Do you agree that clinicians/ clinics should refer to the 'Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm' when considering cognition and language assessments and screening tools?



Summary of comments from Working Group members in poll three

Recommended tools may not be appropriate or feasible for all children – alternate tools should be considered for children who have significant neurosensory impairments so that they are not disadvantaged. Some tools cannot be repeated more than yearly.

Some flexibility should be allowed with timing and frequency of assessment depending on the circumstances of the family and the health professional, and the services available. Every 6 months is not always feasible for the family or the health service.

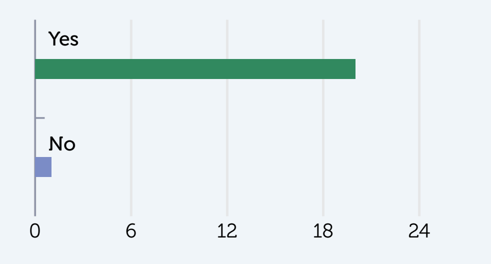
POLL FOUR: JULY 2024
RECAP COGNITION/LANGUAGE AND BEHAVIOUR.

22 participants: 12 parents (54.5%),
3 community health professionals (13.6%),
7 neonatal managers or follow-up professionals (31.8%).

QUESTION 1. Assessment of cognition and language for children at higher risk. Certain formal assessment tools (WPPSI-IV, CELF-P3) should not be administered more than once per year according to their publisher's recommendations.

In line with this, we have now amended our proposal for children at higher risk: These formal assessment tools are not to be administered more than once per year. The assessment to be done in the 6 months in between should focus on specific domains of concern (for example, attention, impulse control, working memory, comprehension, articulation).

Do you agree with this proposal for assessing cognition and language for higher risk children?



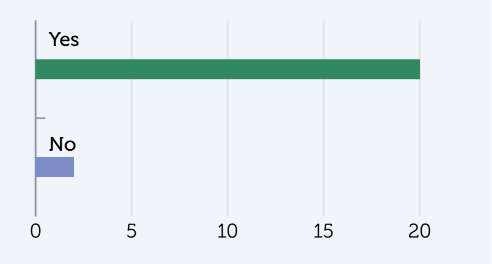
QUESTION 2. Behaviour. Following discussions at the meeting, we propose that:

Children at lower risk are screened twice yearly with a brief parent reported behaviour questionnaire e.g. the Strengths and Difficulties Questionnaire

Children at moderate risk are evaluated once yearly using an in-depth evaluation with a comprehensive behaviour questionnaire, such as the Child Behavior Checklist (parent report plus additional informant if appropriate) and screened once in between with a brief parent reported behaviour questionnaire e.g. the Strengths and Difficulties Questionnaire

Children at higher risk have twice-yearly in-depth evaluations with a comprehensive behaviour questionnaire such as the Child Behavior Checklist (parent report plus additional informant if appropriate)

Do you agree with this proposed procedure for monitoring behaviour?



Summary of comments from Working Group members in poll four

In between those formal assessments of cognition and language, health professionals can use alternate approaches such as observation of a child playing, which can provide rich information on the child's executive function, cognition, social interaction and language.

The Model of Care incorporates flexibility and clinical judgement of health professionals along with parental concerns to ensure that children have any concerns monitored without overdoing it or diagnosing prematurely.

Behaviour is strongly influenced by the family environment. Parental well-being is clearly a factor and is considered nested within the Model of Care to be screened when appropriate.

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