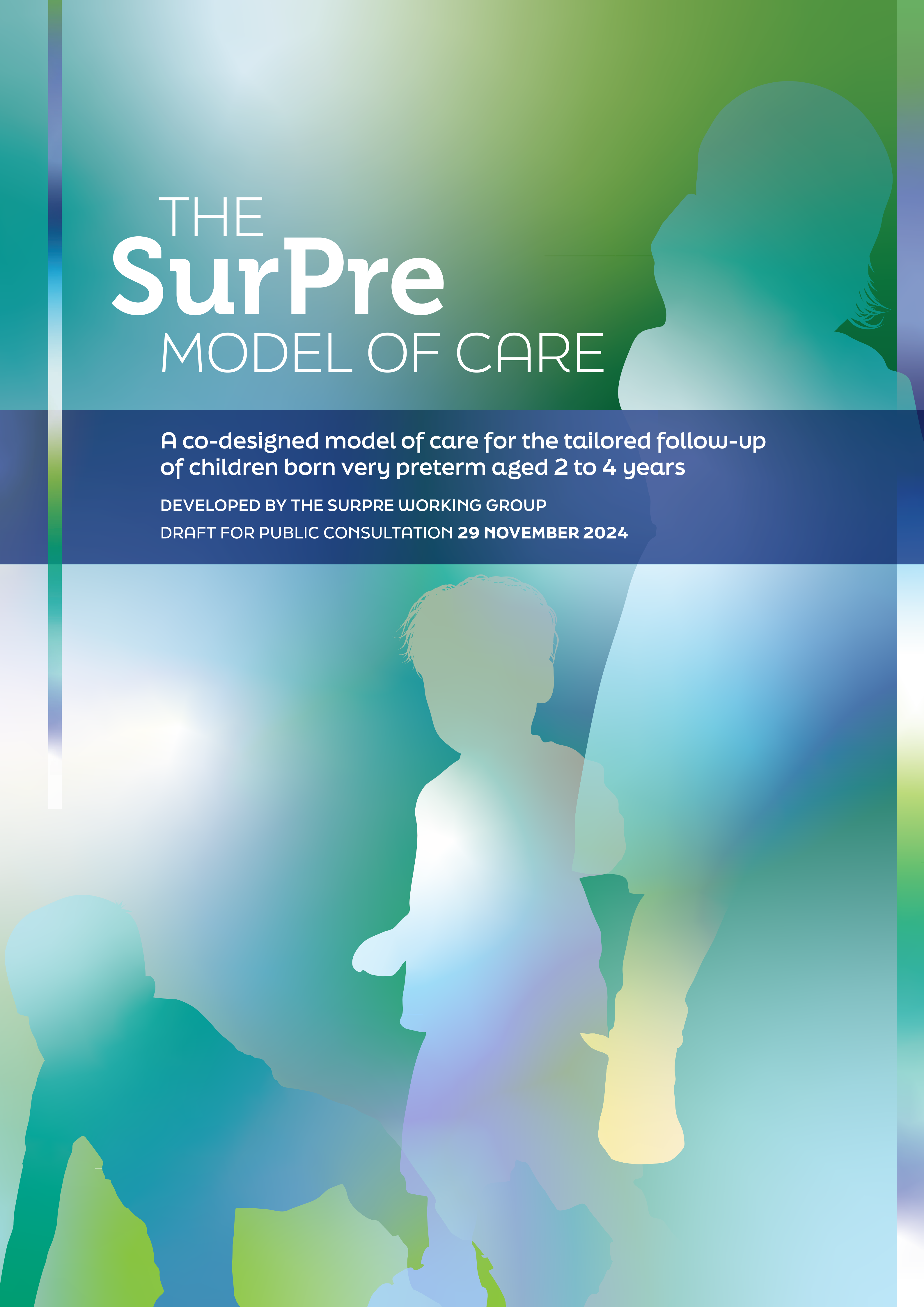

THE
SurPre
MODEL OF CARE

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

DRAFT FOR PUBLIC CONSULTATION **29 NOVEMBER 2024**

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Project governance

The project was guided by a Steering Committee and Advisory Committee who met regularly throughout the study duration.

STEERING COMMITTEE

The Steering Committee comprised the lead investigator (Peter Anderson), three neonatologists (Lex Doyle, Jeannie Cheong, Rod Hunt), one neonatal physiotherapist (Alicia Spittle) and one parent of a child born very preterm (Amber Bates).

ADVISORY COMMITTEE

The Advisory Committee consisted of two neonatologists (Gayatri Jape, Naomi Spotswood), one developmental paediatrician (Marissa Clark), one physiotherapist (Joanne George), one adult who was born very preterm (Thomas Officer), two parents of children born very preterm (Emma Davis, Kylie Pussell), one psychologist (Stephanie Malarbi) and one speech and language pathologist/allied health research director (Kelly Weir).

Funding

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tiny sparks wa

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The Royal Children's Hospital Melbourne

life's little treasures foundation

Monash Children's Hospital

the women's the royal women's hospital

Mercy Health Care first

THE UNIVERSITY OF SYDNEY

THE SurPre MODEL OF CARE

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

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CONTENTS

Report from the chairs

On behalf of our dedicated Working Group and research team, it gives us great pleasure to present this report from the SurPre project: A co-designed model of care for the developmental follow up for young children born very preterm. We thoroughly enjoyed co-chairing such a committed, interactive, and insightful group, made up of hospital and community health professionals and parents with lived experience of caring for children and young people born very preterm.

Our proposed model of care bridges the gap between the early stages of this research project (a worldwide literature review and the building of the developmental concerns prediction model) and the later stages of the project (the implementation, piloting and scaling up of the model). Over the last 12 months, our Working Group has been able to come together regularly in a safe and collaborative online space to take the research findings and use them to develop a family-centred, equitable and feasible model that prioritises effective communication, continuity of care and a holistic child and family perspective.

We are immensely proud of our collective efforts and extend our gratitude to our Working Group for their expert knowledge, honest conversations, openness to others' perspectives, respectful debates and solution-focused work ethic. We have learned a lot together and are very excited to see SurPre progress to the next stage.

Thank you for the privilege of having us co-chair such an important initiative.

Ms. Melinda Cruz
Assoc. Prof. Gehan Roberts

Plain language summary

Children born very preterm (before 32 weeks' gestation) are more likely to experience developmental difficulties such as learning, language and movement problems compared with children born full-term. Some of these difficulties may not show up until the preschool years. Developmental follow-up services for children born very preterm vary considerably across Australia. While it is common for children to be monitored during the first two years of life, there is limited and inconsistent follow-up after this time.

The goal of this project was to create a family-friendly and sustainable care model for children born very preterm focusing on 2 to 4 years of age, the crucial time leading up to starting school. The SurPre Model of Care was co-designed with parents of children who had been born very preterm, community health professionals and neonatal health professionals. A key aspect of the care model is that follow up processes are personalised to the needs of each child and family, depending on their risk for developmental issues. This means that the level of support each child receives will be tailored specifically for them, ensuring they get the best possible care.

Executive summary

Children born very preterm (before 32 weeks' gestation) face a significant risk of developmental challenges, including issues with motor skills, language, cognition and behaviour, compared to their term-born peers without birth related complications. In Australia, there is inconsistency in the identification and follow-up of at-risk children and the timing of these assessments. While extremely preterm infants (born before 28 weeks' gestation) are typically enrolled in health and developmental follow-up programs during their first two years, those born between 28 and 31 weeks often receive limited and inconsistent follow-up. Furthermore, there is insufficient monitoring for these children between the ages of 2 and 4, which is a critical period when developmental concerns can emerge.

The SurPre project employed co-design principles to work collaboratively with parents of children born prematurely, community health professionals and neonatal specialists to develop a model of care focused on targeted developmental surveillance for very preterm children aged 2 to 4 years based on their individual risk profile (The SurPre Model of Care). The co-design Working Group met regularly over a span of 10 months to come to an agreement on how best to monitor the developmental domains of motor skills, cognition, language and behaviour. Under the SurPre Model of Care, a child is categorised as being at lower risk, moderate risk or higher risk for challenges in each of these domains using predictive modelling and discussions with families. A child's level of risk determines the frequency of monitoring, with families receiving contact at least once every 6 months. The care model incorporates six guiding principles; family focused care, continuity of care, access & equity, integrated referral pathways, effective communication and flexibility & feasibility.

Introduction

Context for the project

Very preterm birth (<32 weeks' gestation) is a leading cause of developmental delay in the community, with 70% of surviving children facing ongoing developmental concerns,[1] including cognitive and learning difficulties, language, motor problems, emotional-behavioural issues and social functioning.[2, 3] Accurately predicting which children will experience these challenges remains difficult.[4] Neurodevelopmental concerns may emerge early and persist throughout life, or they may fluctuate with age.[3, 5]

Early developmental delay increases the likelihood of long-term developmental impairments including intellectual disability (ID), cerebral palsy (CP), learning disabilities, autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and anxiety and depression.[1, 6, 7] The impact of developmental problems can be profound for children, families and communities.

Despite the high rates of developmental delay among very preterm children and the potential long-term consequences, there is no universal follow-up system for monitoring these children beyond the age of two. Families often find that existing follow-up programs are generic and do not adequately address their specific needs.[8-11] The primary aim of neurodevelopmental follow-up is to detect developmental issues early, facilitating timely referrals for early interventions to support children in reaching their developmental potential.

Across Australia, there is inconsistency as to which children born very preterm receive follow-up, the methods used, and the timing of these assessments. Although specialised neonatal follow-up is recommended for high-risk groups, resource limitations mean that not all infants receive the necessary services.[12, 13] Typically, neonatal follow-up programs are funded only for monitoring the development during the first two years of life, which is inadequate as issues may not become apparent until after this period.[12] Consequently, there is a significant gap in adequate follow-up for very preterm children between the ages of 2 and 4.

The literature offers limited evidence on how follow-up services are structured in Australia, New Zealand and other countries to meet individual and family needs. Few programs in Australia extend beyond two years, and where follow-up is available in other countries, details about the frequency and customisation of these programs are scarce. Research indicates that many families do not attend follow-up services due to costs, travel times, and a lack of perceived importance.[10, 11, 14-17] In Australia, around 15% of children born extremely preterm or with extremely low birth weight miss follow-up during the toddler period (National Health and Medical Research Council, 2024). Insights from the literature, combined with consultations with families and healthcare professionals, have revealed key factors that either support or hinder follow-up care. These facilitators and barriers have enriched our understanding of the family experience and the challenges they encounter on their journey. This knowledge has been crucial in developing a tailored follow-up care model that addresses the unique needs of both families and healthcare providers.

Aims of the project

The overall aim of the "Targeted Surveillance of Developmental Delay and Impairments for young children born very preterm (SurPre)" project was to enhance support for developmental delay in children born very preterm, by creating a family-friendly and sustainable follow-up model of care for those aged 2-4 years.

The SurPre Model of Care was co-designed with parents with lived experience, community health professionals, and neonatal experts to ensure the program is both acceptable and feasible for families and healthcare providers. From the outset of the co-design phase, a key component of the care model was that follow-up would be tailored to the unique needs of each child and family, based on their risk levels and profiles. This approach is intended to be applicable across Australia.

The SurPre Model of Care specifically targets the third and fourth years of life for several reasons:

1) there is currently no systematic follow-up model for very preterm children beyond 2 years of age;
2) this is a critical developmental period when difficulties often emerge;
3) it is the ideal time to intervene for children with motor, cognitive, language, and behavioural delays as foundational skills are rapidly emerging; and 4) early intervention referral pathways are often available for children in this age group.

The guideline for growth, health and developmental follow-up for children born very preterm

In June 2024, the Centre of Research Excellence in Newborn Medicine, based at the Murdoch Children's Research Institute, published the Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm.[18] This guideline makes recommendations for a structured, preterm specific post-discharge follow-up and puts forward clinical practice points, which underpinned the development of the SurPre Model of Care.

The guideline recommends that:

1) At 2 years of age, children have a formal developmental assessment, preferably face to face, to assess cognition, language, communication and motor abilities and screen for emotional-behavioural concerns.
2) At 4 years of age, children have a formal cognitive, pre-academic skills, behaviour, language/communication and motor skills assessment.

Purpose of the report

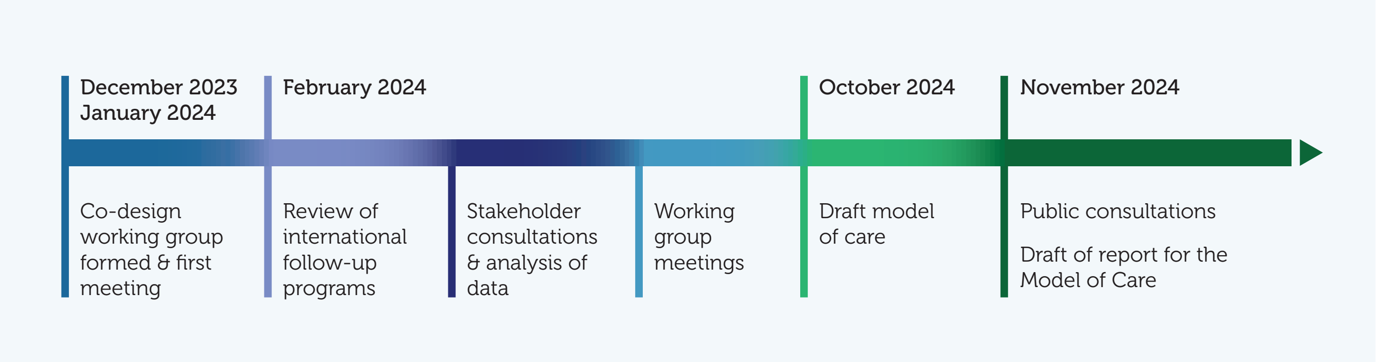
This report outlines the co-designed model of care for the developmental follow-up of very preterm children aged 2 to 4 years tailored to align with each the child's level and profile of risk (The SurPre Model of Care).

Method of approach

The co-design process utilised both quantitative and qualitative methods and consisted of several stages. It was grounded in genuine stakeholder engagement, involving parents with lived experience, representatives from neonatal parent support groups, neonatal specialists, and community health professionals. A literature review and stakeholder consultations were conducted to inform and guide the activities of a Working Group which met 7 times over a period of 10 months.

The final structure of the model of care was established through consensus among Working Group members, facilitated by online polls. For an overview of the project timeline, please refer to Figure 1.

FIGURE 1: THE TIMELINE OF THE PROJECT



Literature review - executive summary

Our literature review concentrated on two main areas:

1) existing national and international care models for children born very preterm aged 2 to 4 years; and
2) parental perspectives on follow-up care and the key elements they value.

This was conducted by searching online content and the peer-reviewed literature using relevant keywords, with a specific emphasis on the 2–4-year age range. The complete literature review is available in the Supplementary Reading document.

Models of care

Most western countries, including Australia and New Zealand, have documented their follow-up programs. Eligibility for high-risk infant follow-up is primarily based on gestational age and birth weight, although some regions also consider the duration on an infant's stay in the Neonatal Intensive Care Unit (NICU). Generally, follow-up occurs until the age of 2, with varying extensions from 3 years to school entry, around 5 to 6 years. Monitoring typically covers several developmental domains including behaviour, cognition, language, and motor skills. Descriptions of these programs are detailed in the Supplementary Reading (Tables 1a and 1b).

Policies & guidelines

Recommendations for follow-up are diverse. 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.[18] In Europe, national and regional policies vary widely, with follow-up ages ranging from 3-4 years to 6-7 years depending on the country.[19-21] Other countries have specific recommendations: Canada suggests monitoring until 3 years of age[22], Texas until 5-7 years of age[23], India until 8 years[24], and Spain until 14 years.[19]

Most guidelines address follow-up age, while fewer detail the nature of follow-up. For example, the Indian National Neonatal Forum Clinical Practice Guidelines advocate for a multidisciplinary team for high risk children, whereas low-risk children are only managed by a paediatrician.[25] The American Academy of Paediatrics also recommends a multidisciplinary approach.[26] The European Standards of Care for Newborn Health (European Standards of Care for Newborn Health, 2018) advise neuromotor follow-up into school age and cognitive assessments during secondary school. Additionally, the UK's National Institute for Health and Care Excellence Guidelines[27] recommend in-person developmental assessments at 2 and 4 years covering most developmental domains.

Guiding principles

Several guiding principles have been proposed to enhance the quality and delivery of follow-up care. One study recommends that follow-up should include hearing, vision, language, behavioural and psychosocial skills, with flexibility for regional or rural settings where access to health professionals may be limited.[28] Other reports emphasise that follow-up should be family-centred, with health care providers communicating the importance of appointments and the goals for the child.[29] Flexibility in delivery formats, such as face-to-face or telehealth options is also recommended, along with consistency in assessment tools used.[30] Monitoring for common disabilities should be linked to key milestones or transitions, like starting school.[15]

Various frameworks have been proposed to assist in monitoring preterm children, some focussed on follow-up care and family needs[30], while others help paediatricians determine the appropriate level of follow-up for each child.[26] The perspectives of health professionals on follow-up care are crucial, particularly in relation to the limitations imposed by resource constraints, funding issues and staff shortages.[13, 14, 29]

Uptake of follow-up services

(PARENTS' PERSPECTIVES)

Research indicates that several factors influence parents' willingness and ability to attend follow-up appointments. Key issues include travelling difficulties, parental concerns about their child and understanding the purpose of these appointments. Supplementary Reading Table 2 summarises parents' views on the barriers and facilitators that impact their engagement with child developmental monitoring. Broadly these include parental and health professional knowledge, accessibility of services, communication methods, social factors, and the type of care available.

Special considerations

PARENTS' MENTAL HEALTH

Parents have expressed a strong need for long-term emotional support, particularly in regional and rural areas, where local peer support groups are often limited.[9, 11, 16] Barriers to accessing this support include inadequate referrals and a lack of awareness about available resources.[10] The World Health Organisation recommends incorporating peer support groups into post-discharge follow-up care for parents of preterm infants to help address these needs.[17]

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

Preterm birth rates are twice as high among Indigenous Australians, and research indicates that Aboriginal and Torres Strait Islander peoples are also less likely to engage with maternal and child health services compared to non-Indigenous families.[41, 43] This disparity has been attributed to language barriers and past negative experiences involving culturally inappropriate or unsafe care delivery.[40, 41]

CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUND

Evidence indicates that individuals from culturally and linguistically diverse (CALD) backgrounds often encounter barriers to accessing appropriate care.[38, 39] Barriers include communication difficulties, lower health literacy, and a lack of transportation.[38] Research has shown that children from CALD backgrounds who are low birthweight or born prematurely experience higher rates of chronic diseases and language delays compared to their non-CALD peers.[38, 44]

Stakeholder consultations – executive summary

The aim of the stakeholder consultations was to gather insights and experiences from families and healthcare professionals on barriers and facilitators to effective follow-up for children aged 2-4 years.

To capture a diversity of perspectives, participants were recruited widely through national networks (professional and family support groups) and existing contacts of the investigator team and the Steering and Advisory Committees utilising an online expression of interest form. In total, 22 parents (21 mothers and 1 father) and 15 community health professionals participated. Participants were representative of all Australian states and territories, except Tasmania, with 27 from metropolitan and 10 from regional, rural or remote locations. The consultation included seven online focus groups and two one-on-one interviews.

Main findings

Several common themes emerged from the consultations:

Continuity and Consistency of Care: Participants emphasised the importance of seamless care experiences.

Single Point of Contact: Families expressed the need for one main contact person over the follow-up period to streamline communication and support.

Support Networks: There was a strong desire for established support networks for families.

Family Education: Providing education to families to empower them with knowledge about what to expect during follow-up.

Context of Follow-up Care: Many families reported distress when returning to the NICU environment, highlighting the importance of considering the environment and location of care.

Mental Health Support: Mental health support for families was identified as a high priority.

In addition, community health professionals noted:

Service Delivery Pragmatics: The effectiveness of service delivery often depended on the specific services available at different sites.

Tracking Systems: There is a need for efficient systems to track children and families throughout the follow-up process.

Upskilling Local Professionals: Support and training for local health professionals were deemed essential for delivering care more locally.

More details on the methodology and consultation findings are presented in the Supplementary Reading.

The SurPre Working Group

The Working Group was established to collaboratively design the SurPre Model of Care, drawing insights from their personal experiences, the literature review and stakeholder consultations. This participatory design approach engaged end users, including parents with lived experience and health professionals. The group was co-chaired by Dr Gehan Roberts, a developmental and behavioural paediatrician, and Melinda Cruz, a parent with lived experience.

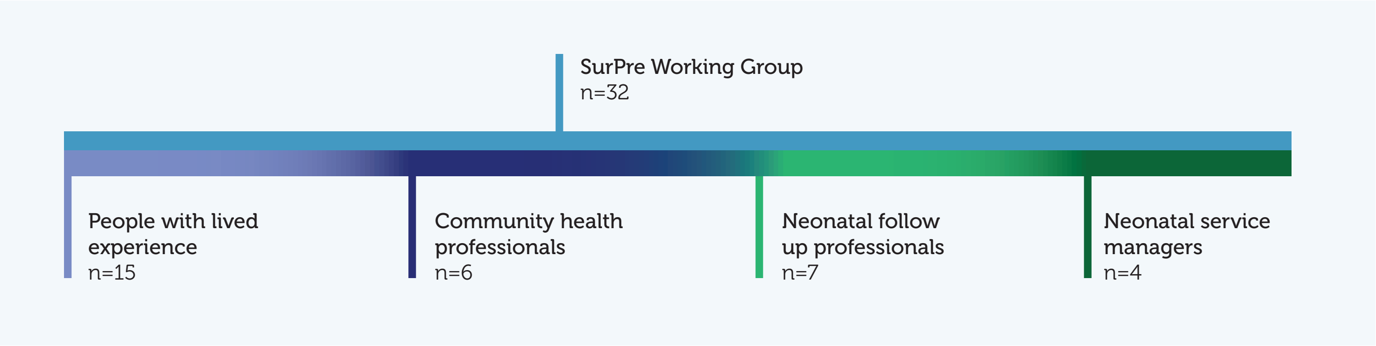
Selection process:

Working Group members were recruited purposively from various stakeholder groups, including parents with lived experience, community health professionals, neonatal managers and neonatal specialists across Australia and from different settings (metropolitan, regional, rural, remote). Recruitment was conducted similarly to the stakeholder consultations, utilising professional and family support groups, as well as known contacts of the study team and advisory groups, through email invitation.

The Working Group comprised 32 members representing diverse stakeholder groups from different regions across Australia (Figure 2):

1) **Parents:** 13 parents of children born very preterm and 2 representatives from preterm parent support groups (Tiny Sparks and Life's Little Treasures Foundation),
2) **Community health professionals:** 6 health professionals working in paediatric community services,
3) **Neonatal specialists:** 7 health professionals working in newborn medicine or newborn follow-up programs, and
4) **Neonatal Unit directors:** 4 directors or managers of neonatal intensive care units.

FIGURE 2. STRUCTURE OF THE SURPRE WORKING GROUP



Co-design meetings

The Working Group met regularly online via Zoom from November 2023 to September 2024 to discuss the development of the care model including risk classification, developmental domains, and the tailoring of follow-up for individual children (Figure 3). Each meeting focused on one or more relevant topics in the model's development. The first two meetings served as introductory sessions. From March 2024, each meeting included background information on a specific topic, followed by prepared proposals debated in small break-out rooms. This was followed by a general full group discussion (Figure 4). Based on these discussions formal structural proposals were presented in an online consensus poll for all Working Group members to complete.

FIGURE 3. **WORKING GROUP MEETING DATES AND TOPICS**

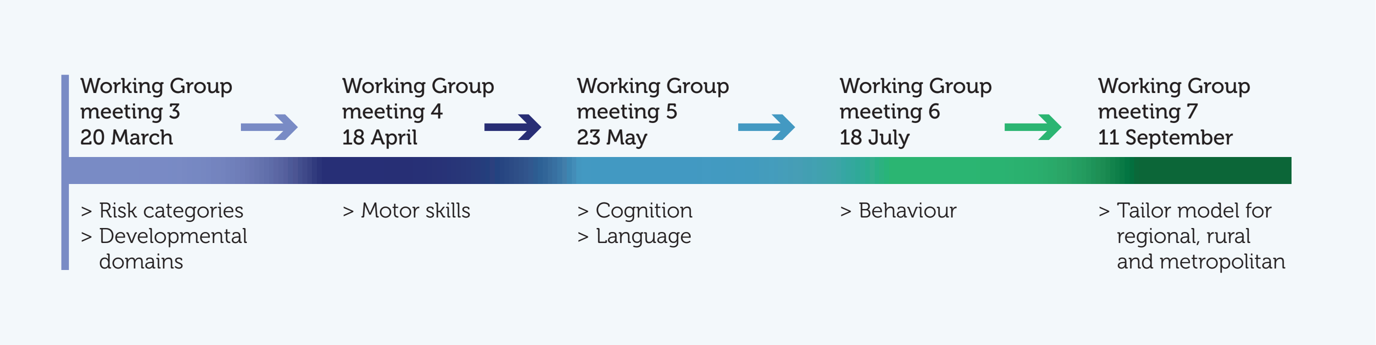
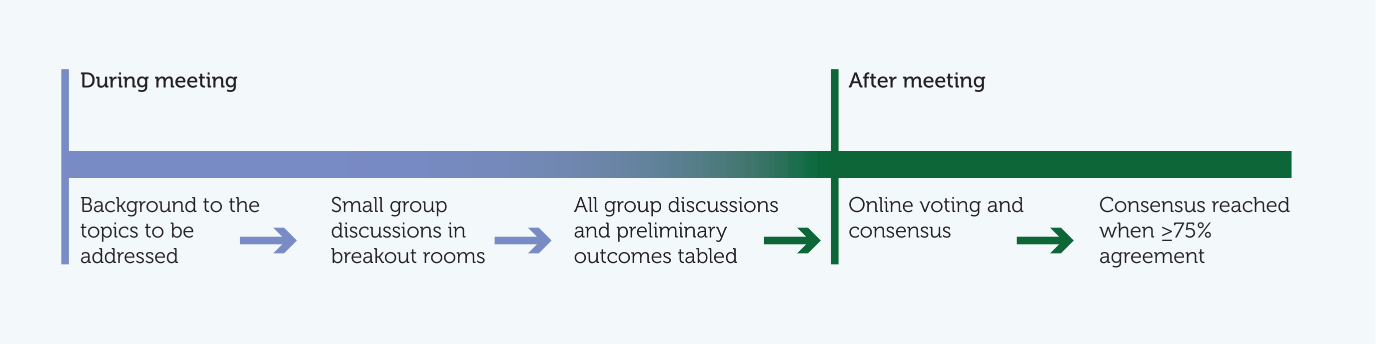


FIGURE 4. **MEETING PROCESS FOLLOWED IN EACH WORKING GROUP MEETING**



The SurPre Model of Care

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

The SurPre Model of Care involves monitoring children at six monthly intervals over a two-year period, specifically in the third and fourth year of life. Monitoring will be tailored based on a child's individual risk classification in each of four developmental domains, and therefore will vary from child to child. The Model includes recommendations for different screening and assessment tools to be used depending on the child's age and their level of risk in each developmental domain.

Developmental domains

The SurPre Model of Care includes monitoring of the following developmental domains:

> **Motor Skills:** ability to control and coordinate movements (e.g. walking, playing with toys)

> **Cognition:** how children think, explore, and figure things out

> **Language:** ability to effectively communicate and understand

> **Behaviour:** actions, reactions, and functioning in response to everyday environments and situations.

Risk classification

Monitoring for each child is tailored to their specific needs and based on one of three risk classifications for developmental issues within each domain.

> Lower risk
  The lowest level of monitoring

> Moderate risk
  Medium level of monitoring

> Higher risk
  The highest level of monitoring

A baseline assessment is recommended at 24 months, corrected for gestational age at birth. During this assessment, the clinician inputs relevant perinatal and early developmental information into a digital tool called VP-Risk. This tool then generates a risk profile for the child in each of the four developmental domains. VP-Risk was specifically designed for this purpose, and the risk profiles it produces are based on extensive research data from over 2,500 children born very preterm. Additionally, the clinician will incorporate parental insights regarding their child's strengths and concerns, family circumstances, the child's overall health, and current access to and use of services before determining a final risk classification.

The SurPre Model of Care assesses four developmental domains—cognition, language, behaviour, and motor skills—providing each child with a risk classification for each. Monitoring is tailored to the child's risk level in each domain, which may vary across the domains.

Flexibility in risk classifications

Risk classifications are designed to be flexible (see Figure 5), allowing children to be reassigned to a higher or lower risk classification at the discretion of the developmental follow-up team. For example, changes in classification may be based on new information such as results from recent screening or assessments, as well as input from the child's family.

SCREENING AND FORMAL ASSESSMENT	
Screening	**Screening** involves identifying the potential presence or risk of a specific developmental problems. For the SurPre Model of Care, it is recommended that a reliable and validated questionnaire be used to screen for cognition, language, motor skills and behaviour issues. If any concerns are identified during screening, this should be discussed with families and in some cases, the child's level of risk may be adjusted, or a referral is made to specialist assessment services. Families should have the option to complete screening tools independently or with the support of a health professional.
Formal assessments	**Formal assessments** are intended to identify whether a problem exists, and to determine its severity. This typically involves an in-person standardised assessment during which a health professional interacts with the child to evaluate various skills. This process provides a much clearer understanding of the child's development compared to peers or age-expectation.

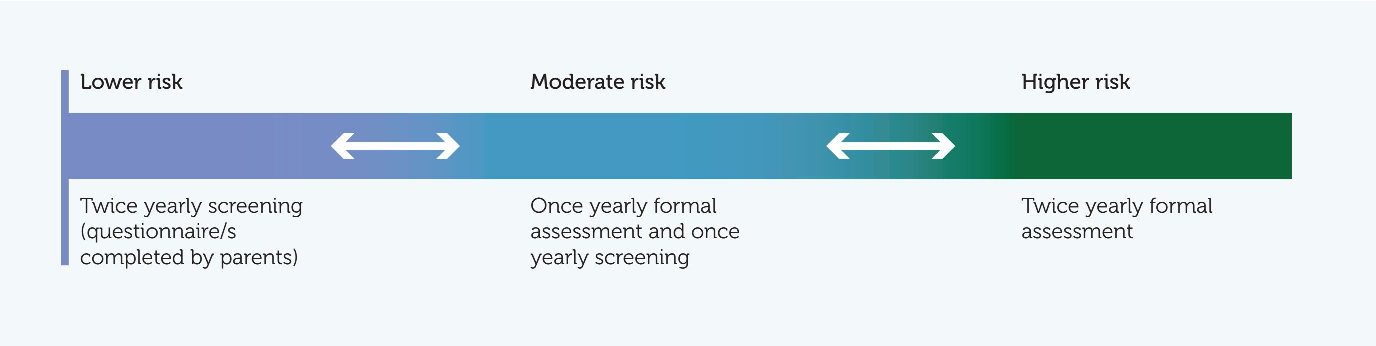
Monitoring schedule

All children should receive some level of monitoring every 6 months for every developmental domain.

1) **Lower risk classification:** For domains classified as lower risk, screening is completed twice a year.
2) **Moderate risk classification:** For domains classified as moderate risk, formal assessments are recommended at 36 and 48 months with screening in the 6 months between assessments.
3) **Higher risk classification:** For domains classified as higher risk, formal assessments are recommended every 6 months.

This tailored approach ensures that each child receives appropriate support based on their individual developmental needs.

FIGURE 5. TAILORED LEVEL OF MONITORING FOR EACH INDIVIDUAL DOMAIN BASED ON CLASSIFICATION OF RISK



Schedule of screening and assessments

The SurPre Model of Care advises health professionals to refer to the Centre of Research Excellence in Newborn Medicine Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm[18] when selecting assessment and screening tools for each developmental domain.

Table 1 outlines the Model's schedule and lists suitable screening and assessment tools informed by the Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm.[18] This structured approach ensures that each child receives the appropriate level of support based on their individual needs.

ASQ-3: Ages & Stages Questionnaires® Third Edition, CBCL: Child Behaviour Checklist, CELF-P3: Clinical Evaluation of Language Fundamentals Preschool-3, PLS-5: Preschool Language Scales Fifth Edition, MABC-2: Movement Assessment Battery for Children, 3rd Edition, SDQ: Strengths and Difficulties Questionnaire, WPPSI-IV: Wechsler Preschool and Primary Scale of Intelligence Fourth Edition.

TABLE 1: THE SURPRE MODEL SCHEDULE OF ASSESSMENTS AND SCREENING

DOMAIN	AGE*	LOWER RISK	MODERATE RISK	HIGHER RISK
Cognition	30 & 42 months	Screening (ASQ-3)	Screening (ASQ-3)	Assessment (WPPSI-IV)
	36 & 48 months	Screening (ASQ-3)	Assessment (WPPSI-IV)	Focused assessment
Language	30 & 42 months	Screening (ASQ-3)	Screening (ASQ-3)	Assessment (PLS-5)
	36 & 48 months	Screening (ASQ-3)	Assessment (CELF-P3)	Assessment (CELF-P3)
Motor	30 & 42 months	Screening (ASQ-3)	Screening (ASQ-3)	Assessment (MABC-3)
	36 & 48 months	Screening (ASQ-3)	Assessment (MABC-3)	Assessment (MABC-3)
Behaviour	30 & 42 months	Screening (SDQ)	Screening (SDQ)	In-depth (CBCL)
	36 & 48 months	Screening (SDQ)	In-depth (CBCL)	In-depth (CBCL)

**Corrected for gestational age at birth*

Completion of program

At the child's final scheduled appointment at 48 months of age, the follow-up team should prepare a comprehensive report outlining the child's developmental status, including:

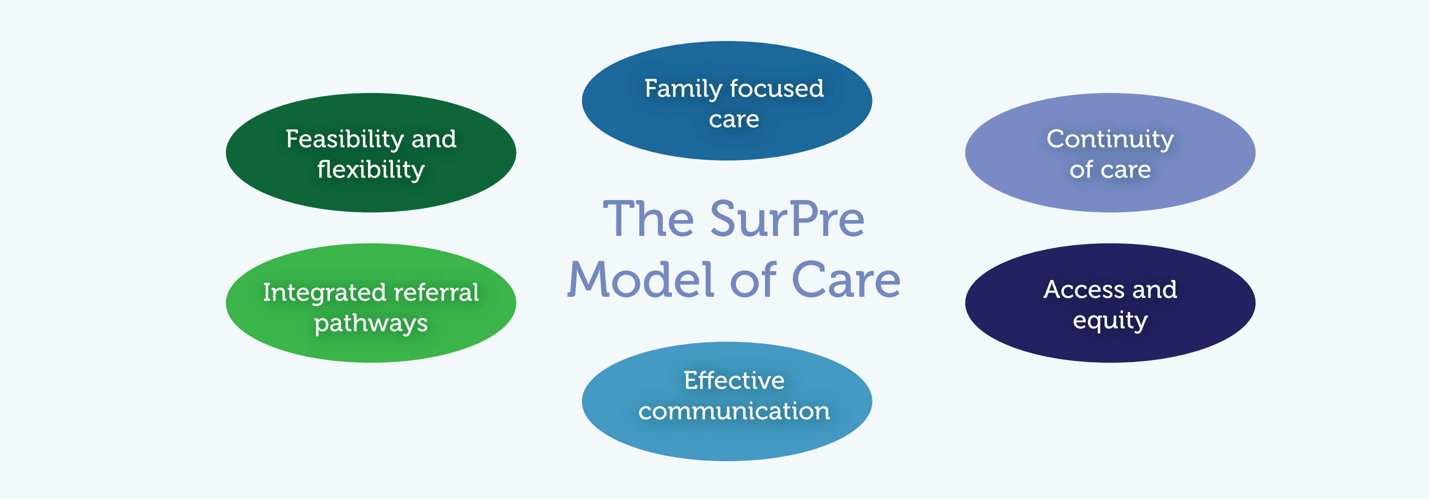
- An overview of progress in each developmental domain.
- Recommendations for any ongoing monitoring or follow-up care.
- Insights into the child's school readiness, discussed with the family.

This final assessment aims to give families a clear understanding of their child's development and the next steps to support their continued growth and learning. The family may choose to share this report with other health or education professionals as needed.

Guiding principles underpinning the SurPre Model of Care

The Working Group established six key principles that guide the SurPre Model of Care (see Figure 6).

FIGURE 6. THE SURPRE MODEL OF CARE GUIDING PRINCIPLES



1. Family-focused care

Follow-up teams should prioritise the family context. Health professionals are encouraged to place families at the centre of care, involving parents in the monitoring process and consultations about risk classification. This approach ensures that care is individualised and meets the specific needs of both the child and family. Feedback on assessments and screening should be shared with families, emphasising their insights on their child's strengths and challenges.

PARENTAL MENTAL HEALTH CONSIDERATIONS

Recognising the importance of parental mental health to child development, the Model recommends screening parents for mental health and well-being. Relevant support services should be suggested if needed. Self-report screening tools such as the Centre Epidemiologic Studies Depression Scale (CES-D), the General Anxiety Disorder-7 (GAD-7), the Hospital Anxiety and Depression Scale (HADS), the Depression Anxiety Stress Scale (DASS) and the K10, can be utilised.

2. Continuity of care

Continuity of care is vital for children and families. When referrals to other services are made, continued monitoring of developmental domains should occur, with regular communication between follow-up teams and other services.

3. Access and equity

Ensuring equitable access to the follow-up program for families is crucial to promoting fairness and supporting their diverse needs, regardless of their background or circumstances. This involves addressing potential barriers such as geographic location, socioeconomic status, language, or cultural differences, which could prevent some families from attending appointments. Equitable access also means providing resources and accommodations to meet the unique needs of families, ensuring that all children, particularly those from vulnerable or marginalized groups, can benefit from the follow-up program.

RURAL AND REMOTE CONSIDERATIONS

Health services should take travel times and logistics into account when planning appointments.

Possible options for making appointments more accessible to rural and regional families include:

- Telehealth consultations.
- Coordination with local health services. Combined efforts of follow-up teams and local health professionals, potentially using telehealth for certain assessments.

CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) AND INDIGENOUS CONSIDERATIONS

Health professionals should be aware of cultural differences and offer local support or interpreters as needed. Some screening tools may need to be replaced with alternatives, such as the ASQ-TRAK for Aboriginal children.

4. Effective communication

Open and timely communication is essential to the success of the SurPre Model of Care. Families should receive informative feedback after each screening and assessment, along with discussions about processes and strategies for the following six months. Opportunities for families to provide feedback should be included. Clear communication empowers families to make well-informed decisions that support their child's development.

HEALTH LITERACY CONSIDERATIONS

Consideration of families' health literacy is a critical aspect of ensuring that all families can fully engage with the follow-up program and make informed decisions about their child's care. Health literacy refers to the ability to understand, interpret, and apply health-related information, and it can vary significantly across different families. To support families effectively, it is essential that information is communicated in simple, clear language, free from complex medical terminology or jargon that might be confusing or overwhelming.

Written materials should be tailored to the family's level of understanding, ideally at an 8th grade reading level, to ensure accessibility. Information should be organised in a logical, easy-to-follow structure, with important details highlighted to ensure they stand out.

Offering opportunities for families to ask questions and engage in discussions with healthcare providers also ensures that they fully understand the information and can act on it appropriately.

5. Integrated referral pathways

The SurPre Model of Care recommends referrals for specialist evaluations as necessary, for example, assessment for autism or cerebral palsy. Follow-up teams should coordinate with specialists to avoid duplication of assessments and ensure continuity of care. Additionally, children should be referred to the appropriate intervention services as needed, with ongoing monitoring by the follow-up team.

6. Feasibility and flexibility

While the primary goal of the SurPre Model of Care is to identify children early who may benefit from additional support and referral to appropriate intervention services, it is important to acknowledge that access to these services is not always straightforward or readily available. Families may encounter challenges such as long waiting lists, geographic barriers, limited service providers, or a lack of specialised programs in their local area. It is essential that families are fully informed about these potential difficulties upfront, so they have realistic expectations and can plan accordingly.

Further, not all elements of the SurPre Model of Care may be feasible for every follow-up program, particularly in locations with limited resources, expertise, or infrastructure. For example, some programs may not have the capacity to conduct certain assessments or may need to rely on telehealth services where in-person visits are not possible. Adjustments should be made based on the specific needs and available resources in each community or healthcare setting. These adjustments should still maintain the core goal of providing early identification and referral to appropriate intervention, but with a practical, locally adapted approach that ensures families can access the best possible care within their own circumstances.

Flexibility and collaboration with local clinicians, service providers and community health professionals are key to overcoming these barriers and ensuring that all families, regardless of where they live or what resources are available to them, can benefit from timely assessment and support.

Public consultation

The SurPre Model of Care Report will be disseminated widely for public consultation during December 2024 through various networks of those with lived experience and other stakeholders, including participants from the consultation phase. This process will allow individuals to provide feedback, facilitating further refinement of the SurPre Model of Care. Dissemination efforts will include invitations for feedback through established networks and an open online forum to ensure comprehensive stakeholder input.

Future directions/ next steps

After the public consultation, the SurPre Model of Care Report will be finalised and distributed widely.

Between 2025 and 2027, the SurPre Model of Care will be evaluated in a feasibility study involving families with 2-4 year-old child born very preterm in Victoria. In this feasibility study we will survey all participants (including family members, healthcare professionals and newborn follow-up clinics) to better understand:

- Family satisfaction in relation to the SurPre Model of Care
- Health professional satisfaction in relation to the SurPre Model of Care
- Referral to support services as a direct result of the SurPre Model of Care
- Family satisfaction with the services they were referred to during their involvement in the SurPre Model of Care
- Cost-effectiveness of the SurPre Model of Care.

Based on the findings from this evaluation, and further consultation with the major stakeholders the Model of Care may be further refined. Following this refinement, an implementation toolkit will be developed for use by preterm-specific follow-up services across Australia.

GLOSSARY

Behaviour: Refers to how one conducts themselves. It is actions, reactions and functioning in response to everyday environments and situations. Children are continuously learning how to manage their emotions and conform to the behavioural expectations of the world around them. Challenging behaviour is a term used to describe behaviour that interferes with a child's daily life.

Co-design: A participatory approach to research, in which end-users (in this case families and health care professionals) are treated as equal collaborators in the process and engaged meaningfully in the research design and across all stages of the research process.

Cognition: A term for the mental processes that take place in the brain, including thinking, attention, language, learning, memory and perception. Cognitive development means how children think, explore and figure things out. It is the development of knowledge, skills, problem solving and dispositions, which help children to think about and understand the world around them.

Focus Group: A form of qualitative research in which a group of people are asked about their attitude and/or feelings towards a topic or idea. Questions are asked in an interactive group setting where participants are free to discuss with other group members.

Follow-up: The act of contacting patients or their caregivers at a later, specified date to check on progress since their last appointment. The ongoing evaluation of a child who has an increased risk of developing a concern to detect any developmental concerns early.

Formal assessment: This is usually an in-person standardised assessment where a health professional spends some time with the child to assess a number of different skills that give a much clearer understanding of where that child is compared to their peers or compared to their age-expectation.

Language: Language development in children is the process through which they gain the ability to effectively communicate (expressive language) and understand (receptive language).

Model of care: This broadly defines the way health services are organised and delivered. It is usually person-centred and a principle-based guide.

Motor skills: The skills used to control and coordinate movements. It involves tasks that require voluntary control over movements of the joints and body segments to achieve a goal e.g. crawling, getting up from the floor, walking, manipulating objects with the hands.

Preterm birth: Babies born alive before 37 weeks of pregnancy are completed. Very preterm includes babies born less than 32 weeks

Risk: The probability or chance of a child having developmental challenges due to earlier circumstances. Risk factors are things that come before and increase the likelihood of poor outcomes/challenges in neurodevelopment. Lower risk = Lowest level of monitoring; Moderate risk = Medium level of monitoring; Higher risk = Highest level of monitoring.

Screening: Screening instruments are designed to identify the potential presence of a particular problem/issue. For SurPre, this is usually a quick assessment like a questionnaire. It is designed to identify which children are at higher risk for developmental challenges in a particular area; if there are any areas of concern and whether a child would benefit from further detailed "formal" assessment.

Stakeholders: People or organisations who have an interest in the research project or affect or are affected by its outcomes. For SurPre, this includes families of children born very preterm, community health professionals and neonatal services.

Working Group: A group of experts working together to achieve specified goals, with defined purpose, goals, roles and responsibilities.

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