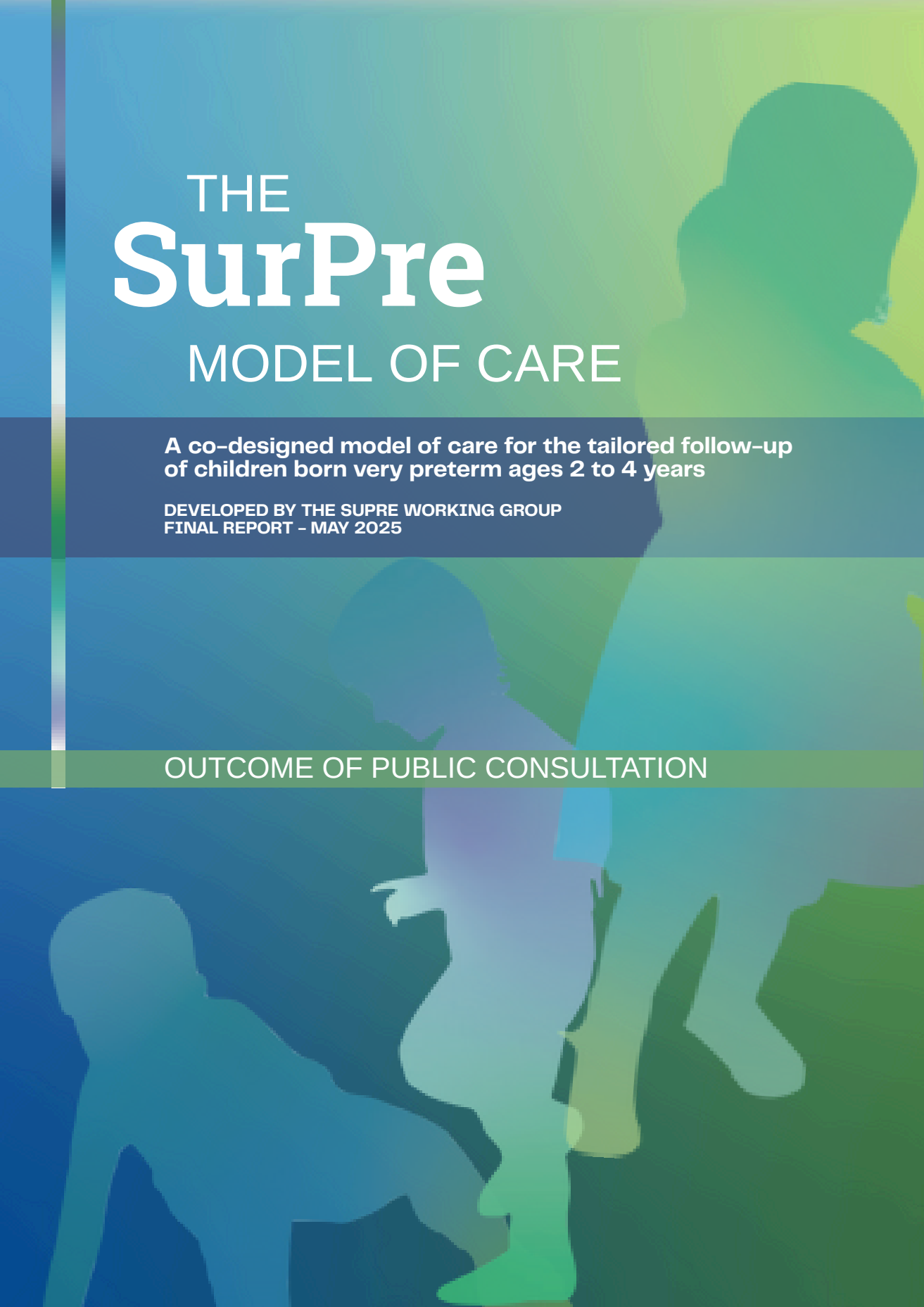
THE SurPre MODEL OF CARE

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

DEVELOPED BY THE SUPRE WORKING GROUP
FINAL REPORT – MAY 2025

OUTCOME OF PUBLIC CONSULTATION



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THE SurPre MODEL OF CARE

BACKGROUND

Between October and December 2024, a draft of the SurPre Model of Care was circulated for consultation with key stakeholders, including health professionals, parents, and researchers. The purpose was to gather feedback on the proposed approach to developmental follow-up for preschool children born very preterm. The report was distributed to over 100 individuals and organisations, with 15 responses received. Feedback was constructive and informed minor revisions ahead of the next phase of feasibility testing and implementation planning.

Feedback summary

Neonatal Health Professionals (n=9)

Key Themes

- Strong support for consistent follow-up, but concern about feasibility and resource needs.
- Mixed views on assessment tools, particularly the WPPSI and SDQ.
- Emphasis on the need for clear referral pathways and better integration with existing services.
- Recognition of the importance of continuity and family engagement.
- Suggestions for clearer communication of the model's flexibility.

Community Health Professionals (n=2)

Key Themes

- Strong emphasis on addressing psychosocial and family risk factors.
- Importance of embedding prevention and optimisation principles.
- Concern that families could be lost to follow-up without a clear strategy to address access barriers.

Other Health Professionals (n=1)

Key Themes

- Provided detailed editorial suggestions, particularly around phrasing and clarity.

Parents and carers (n=3)

Key Themes

- Strong endorsement of the model and its goals.
- Emphasis on rural access, continuity of care, and parent mental health.
- Practical suggestions regarding the NDIS and support for families post-discharge.

Full feedback and responses

Table 1. Feedback and responses organised by respondent group

Respondent	Feedback received	Response
Neonatal Health Professional #1	Overall, I agree this group requires a consistent follow up programme. I question where the resources will come from. As a NICU follow group we do not have the capacity to do further follow up and already struggle to get children who we identify as requiring support at their 1 or 2 Bayley assessment.	Feasibility of this program is a very important issue. This was discussed by the Working Group which consisted of neonatal follow-up health professionals as well as some NICU Clinical Directors. Our next task is to conduct a feasibility study of this Model of Care in Victoria. The feasibility study will evaluate the level of satisfaction with the program from parents, follow-up health professionals, and NICU Directors. We will also be performing a health economic analysis to determine the cost of the program as well as the economic benefit. While we acknowledge that funds would be needed to extend current follow-up services, we expect that this would be at least partly offset with reduced health burden to the child and family. Our premise is that children who are in need for support will be identified earlier and referred to the most appropriate services available at the most appropriate time resulting in improved outcomes and less reliance on health and educational resources.
Neonatal Health Professional #2	One of the feedback points from families and healthcare professionals on *Table 3, pg. 15* of the Supplementary Material Guide, is to have a single point of contact, such as a clinic nurse coordinator, as it significantly improves family engagement and reduces family stress. Does the SurPre model recommend a research nurse/clinic coordinator, make the follow up appointments for speech pathology services (to complete the CELF-P3 and PLS-5 assessments) on the family's behalf? Or is the family expected to make these appointments for follow up based on speech pathology referrals made at the 2-year review? Will SurPre recommend specific Speech Pathologists to provide this service, or is it up to the sites to make referrals based on their usual referral process?	Continuity of care with the follow-up team was a strong recommendation from families, and as such the SurPre Model of Care encourages follow-up teams to aim for consistency in the point of contact for each family as well as the health professionals managing the assessments. However, we also noted that this may not always be possible. The example provided related to Speech Pathology. The Model of Care supports a multi-disciplinary approach with access to paediatrics, psychology, physiotherapy, occupational therapy and speech pathology. While most follow-up services are multi-disciplinary, few have access to all these disciplines. Given that this is a Model of Care, we expect that services will use our recommendations as a framework for designing their program and that services will focus on those elements that they can resource. Out-sourcing those elements that services can't offer is a very reasonable solution.
	Well done to a fantastic document. It's very easy to read with up to date and relevant information from Australia and around the world. Thank you.	Thank you for your comment.
Neonatal Health Professional #3	*Schedule of Screening, pg. 16* Is there a reason why you have not included the ASQ:SE-2 as part of the standard screen? Additionally, why at 30 & 42 months has the SDQ been suggested as a screening tool when there can be continuity in the type of screening used as the ASQ-3 and ASQ:SE-2 goes up 60 months of age.	The screening and assessment measures listed in the Model of Care report are only recommendations and are based on the recently published *Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm*. The Working Group acknowledged that it is appropriate for services and clinicians to use other measures, assuming that they are reliable and valid for screening or assessing the developmental domains. We have added text to the report to make it clear that the listed measures are recommendations only.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
		The Working Group was satisfied that the SDQ was an appropriate screening measure for behavioural and emotional issues, in line with the recommendation from the Guideline.
	Schedule of Screening, pg. 16 I would suggest that the WPPSI is an inappropriate tool for screening/assessment in this age group as it has reduced reliability at 36 months. If there are cognitive concerns, I would advocate that a developmental assessment is much more appropriate. This would be either the Bayley-4 (for up to 42 months of age) or a Griffiths-III which can encompass children aged up to 48 months.	We acknowledge that some tests may not be appropriate for some children and families, with age being one factor. As noted above, we have added text stating that the measures listed in the Model of Care report are a recommendation, and services/clinicians are free to use other measures that are reliable and valid.
	Access & Equity, pg. 18 I do appreciate collaborative frameworks. Currently, our regional and remote Health staff working in community health centres are overwhelmed and cannot take on further work without an injection of resources	The challenges of services to comply with this Model of Care was noted by the Working Group, in particular those in regional and remote areas. The Working Group encouraged services to be family-focused and flexible to ensure that all children received surveillance regardless of their family circumstances.
	Our NICU follow program services a wide geographic area encompassing from the Central Coast to the QLD border. We do provide outreach, but it is funding-based. Telehealth is an option for screening but to offer further assessments would require additional resources as most assessments (e.g., cognitive) require face-to-face appointments.	Funding and feasibility are important issues and will be evaluated in a feasibility study that we will conduct in Victoria. The Working Group discussed a range of options for families that did not have good access to appropriate services. As implied in the Access and Equity section of the Guiding Principles, telehealth can be used with local health professionals who may not have the expertise in very preterm children, and can conduct the assessment in-person, whilst being on telehealth with the follow-up team.
Neonatal Health Professional #4	*Schedule of screening and assessments, pg. 16* This looks great overall. I can imagine that this might represent quite an intensive, lengthy and exhausting assessment for children who are higher risk in multiple domains. I wonder if in some instances what might be almost more helpful is having someone check in with the families to see if they have been able to access early intervention, need support navigating the system rather than having more assessments.	It is accurate that the most intensive surveillance will be offered to those children who are at higher risk in multiple domains, and it is these children who are most likely to be receiving early intervention. The relationship between follow-up teams and intervention services was discussed by the Working Group. The Working Group recommended that children receiving intervention services continue in the follow-up program to ensure that all domains continue to be screened. It was also acknowledged that intervention services vary greatly in terms of content but also frequency, intensity and duration. We have added text that attempts to clarify this point.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
	Whilst great, I suspect this model of care will be very resource intensive. I have met many families who will love having frequent assessment but can also think of plenty who are overwhelmed by their early intervention requirements and might find additional assessment a bit overwhelming. I think it will be very interesting to trial this program and identify what resources required to deliver this type of follow up.	Our feasibility study will assess family satisfaction, as well as satisfaction of NICU follow-up teams and NICU Directors. Costs are an important factor which we will also assess in the feasibility study.
Neonatal Health Professional #5	This document is very confusing, and difficult to understand even for people who do developmental follow-up every day. It is unclear the model of service provision expected.	We are sorry that this report was confusing for you. The aim was to develop a model of care for the surveillance of children born very preterm in Australia aged 2 to 4 years and tailored to their individual needs.
	No current model exists in NSW which would be able to replicate this. This level of screening is beyond that undertaken for extreme prematurity as guided by ANZNN. Why?	We appreciate that many follow-up sites do not currently follow-up these children during this period – that was one of the motivations for this initiative. We also appreciate the approach to tailor monitoring to individual needs is also not an approach used in current settings. The Working Group felt that this was likely to be a more effective approach to supporting children and families, and to result in greater family satisfaction, higher follow-up rates and ultimately more appropriate services for children at the appropriate time. A feasibility study will be conducted.
	Table 1, pg. 16 24 month assessment not included in table which means it is easily missed. Confusing as to whether WPPSI is conducted at both 30 and 42 months (this is very early!)—48 months is an early sign off as many children will not be attending school for another 18 months. No clear guidance in this document regarding risk matrix and whether it will be easily applicable or relevant to our population. 2500 seems a low number to generate a predictive model that will be able to be generalised across AU.	The measures listed in Table 1 are recommendations only and clinicians and services are free to administer reliable and valid clinical tools that they feel are appropriate. The Working Group selected these measures to be consistent with the recently published *Guideline for Growth, Health and Developmental Follow-Up for Children Born Very Preterm*. The important point is that this is a subgroup of children who should receive a formal cognitive assessment at those ages; the measures to be administered will vary depending on clinician, local and child factors. Regarding the predictive modelling, this will be the largest cohort of children born very preterm with detailed prediction and outcome variables. We are confident that our models will be predictive.
	Test choices: It is not clear from this document which neurodevelopmental diagnoses are being targeted as an outcome from screening? Is WPPSI the appropriate test for this age? WPPSI does not permit diagnosis of GDD which would enable access to NDIS and early intervention. Children may not tolerate extensive testing through WPPSI+PLS+MABC. Better suited are comprehensive test such as GMDS or Bayley.	As discussed above, the measures listed in Table 1 are recommended based on the NHMRC endorsed Guideline. Clinicians and services may decide to use alternative measures.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
	This is also less clinician intensive and more sustainable from a service provision perspective.	
	Medical screening: This group is also at risk of other medical sequelae such as hearing impairment, vision impairment, hypertension, epilepsy. It is not clear whether medical screening is included. This would be a missed opportunity.	The terms of reference for this project was to focus on the neurodevelopmental domains of cognition, motor, language, and behaviour. Indeed, children born very preterm are at risk of medical and sensory problems and the individual surveillance team are encouraged to conduct additional assessments as they see appropriate. Currently, at most sites, these children are not formally followed up at all beyond 2 years of age.
	This is a really important body of work which we appreciate fills a much overlooked gap in service. We hope our feedback is able to be incorporated to develop a feasible and sustainable service for these children. Thank you for all of your hard work!	Thank you for your comment.
Neonatal Health Professional #6	*Future directions/next steps, pg. 20* We acknowledge the team's incredible work in developing this model of care, it is considerate of those with lived experience and clinicians alike	Thank you for your comment.
	Our team suggests a second feasibility stage to include a wider range of neonatal-based assessment services in different states, testing the model of care in different healthcare scapes and funding structures. As is identified in your model of care document, communities in metropolitan and rural/remote regions have different needs and capacities for providing assessment services in a timely fashion. A second feasibility stage would ideally include existing, willing, publicly funded developmental assessment services who wish to expand their capacity and would be represented equally by metropolitan and regional communities with varying resourcing. Planning ahead in a coordinated and consistent fashion will be critical to achieving adequate funding toward meaningful change. Some of this planning will need to occur sooner than 2027 to prepare for expanded assessment services if our feedback is accepted. Training and resource acquisition will be key costs to be considered ahead of time. We also feel this step would aid in developing the implementation tool kit.	We agree that the feasibility of this Model of Care needs evaluation. Our proposed feasibility study will be conducted in Victoria by the existing neonatal follow-up teams. This was largely a pragmatic decision, but as you state, further assessment of the program in other states and in different settings is important.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
Neonatal Health Professional #7	*Pg. 16* Who will complete the ASQ and is that expected during clinic time or before assessment face to face. And who collates that data?	The ASQ will be completed by parents. Some parents may wish to do the screening survey on their own, however they should also have the option of doing it with an appropriate health professional over the telephone or using telehealth options. When screening tools are completed depends on what other assessments are scheduled for the child. For children who are classified as lower risk for all domains, surveillance will be restricted to screening using validated questionnaires and in-person appointments are not necessary. However, other children will have a mix of screening and in-person assessments, and in these cases, it would be preferable for the ASQ (or other screening instruments) to be distributed to the family beforehand.
Neonatal Health Professional #8	Lack of resources is the biggest issue with this model. In NSW this model of care is predominantly provided by the NICUS system for infants born <29 weeks, however almost double resources would be needed to cater for the 29-32 weeks group.	This Model of Care is proposing surveillance beyond what most services are currently able to offer. As such, it is acknowledged that additional funds would be required to implement this proposed program. In a feasibility study we will be undertaking a health economic analysis to determine the cost of the program, and the health savings associated with families have access to increased surveillance.
	Who will actually be employing therapists to conduct assessments? This can be problematic unless the private system is utilised, which would have significant conflict of interest issues.	How follow-up services structure their programs, including how health professionals will be contracted, was not discussed by the Working Group. It is an important consideration, and is the responsibility of the individual services.
	Why is there little to no reference of the existing surveillance system set up for extremely preterm infants in NSW?	The Working Group had broad regional and stakeholder representation, including members from NSW. The goal was not to review existing services; rather to design a new model of care taking into account scientific and grey literature, stakeholder consultations, and the views of the Working Group members.
Neonatal Health Professional #9	*Table 1, pg. 16* The model does not take into account feeding and nutritional delays which are often seen in preterm infants even beyond 4 years. A recent meta-analysis by Pados et. al, 2021 found that "Problematic feeding is highly prevalent in prematurely-born children in the first 4 years of life regardless of degree of prematurity. Healthcare providers of children born preterm should consider screening for problematic feeding throughout early childhood as a potential complication of preterm birth. By not screening for feeding and nutritional difficulties, we fail to take into account the impact of feeding and growth on other developmental domains such as motor, language and cognitive development.	We agree that feeding and growth are important aspects of development in children born very preterm. While the primary focus of the SurPre Model of Care is on the neurodevelopmental domains of cognition, language, motor skills, and behaviour (as defined by the project's scope and funding) it does allow for clinical discretion in addressing other areas of concern where appropriate.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
	Introduction, pg. 6 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—This does not include speech and language delays (e.g. receptive + expressive language delays). There is enough literature to state that preterm infants are at higher risk for long-term	On page 6, paragraph 1, we state that children born very preterm are at risk for language problems. The following paragraph which your comment refers to, was focused on specific DSM-5 developmental disorders which have been established to be increased in children born very preterm. Due to a lack of research, there is less evidence that these children are at greater risk for specific language/communication disorders.
	I would like to emphasise that feeding and growth screening should be included at the 2 and 4 yr check-up. Failing to include this, does not give us a global understanding + context of the developmental delays that are being screened/assessed	Thank you for your comment. As mentioned above, the scope of this project specifically addressed neurodevelopmental surveillance. However, the guiding principles of the model, particularly family-focused care and flexibility, support tailoring follow-up to each child's needs, including considering family-reported concerns around feeding and growth. Services are encouraged to incorporate additional assessments, such as feeding or nutrition, where these are relevant to the child's development and wellbeing.
Community Health Professional #1	This report, to my reading, fails to emphasise what I regard as the greatest opportunity to help this group of children. Specifically, this is prevention. The proposal reads as detect then intervene. Prevention means intervening before detection. In early childhood, prevention includes family stability (HOME measures), circadian management, state regulation, attachment messaging reciprocity and a lot more. To my knowledge this has not been studied sufficiently so I cannot cite evidence, however my clinical practice has been unambiguous that managing children from day 1 makes a difference - developmental intervention with a prevention and optimisation purpose rather than treatment of identified problems.	Thank you for your comment. Children born very preterm are at increased risk for neurodevelopmental challenges and as such programs are needed that commence in the NICU and beyond that aim to minimise or prevent the emergence of these developmental problems. Our group and many others have developed and assessed such programs. A Cochrane Review led by our group demonstrates that these preventive care programs for children born preterm enhance early development, in particular cognitive outcome[1] and other evidence exists demonstrating improved behavioural and family outcomes[2].While these preventive care programs are beneficial, children born very preterm continue to have developmental challenges when compared to children born full term. Also, unfortunately these preventive care programs have not been successfully implemented into clinical care in Australia (or most other developed countries) due to their cost and access inequity. We are attempting to address these concerns with programs that are web-based or utilise telehealth. In the introduction we have added a statement regarding preventative care programs—see Appendix for citations.
Community Health Professional #2	*Pg. 17 and 18* Overall, I very much support the model of care. I think we very much need to consider psychosocial risk factors as an integral part of the model of care. These factors are often a large barrier for families in accessing (and actioning recommendations) these services.	The Working Group discussed at length the importance of the child's family context. This is reflected in the guiding principles of the Model of Care. Firstly, we highlight that surveillance should be family focused, prioritising the family context including the emotional state of parents and other family members (page 17).

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
	I think a great majority of families would be easily lost to follow up if the model didn't include a clear approach to navigating this.	Another guiding principle was labelled “Access and Equity”, which acknowledges that the family background, circumstances and geographic location can make it easier or harder to access appropriate services. The report encourages services to take these issues into account and recommends alternative approaches for those families who do not have good access. Finally, flexibility is another guiding principle. The report recommends that clinicians are flexible in the way they structure their program, taking into account family circumstances and working around barriers to ensure all children received high-quality surveillance.
Other Health Professional	*Pg. 6, paragraph 2, first sentence* Current wording makes it sound like the delay causes the impairments whereas they are caused by the prematurity and/or associated complications. Suggest rewording.	This sentence has been amended to: “Very preterm birth increases the risk for early developmental delay and long-term impairments including…”
	Pg. 6, paragraph 3 I think we need to stay away from the terminology 'developmental delay' as we know most of these children never 'catch up. Suggest using developmental deficits/impairments.	This sentence has been amended to: “Despite the high rates of long-term neurodevelopment problems for children born very preterm…"
	Pg. 7 Right hand column under aims Point 4 is in line with point 3 rather than as the next dot point.	Amended.
	Pg. 14, paragraph 2 I note this still refers to inputting of info into the VP-risk tool. I am aware the team will be conducting the feasibility trial using a different strategy of risk identification for understandable reasons. Just wondering if it is ok that this MoC still speaks about the tool?	We have revised this section to read as follows: "A child's level of risk for each developmental domain should be determined at their baseline assessment at around 24 months of age, corrected for prematurity. We are developing a digital tool to assist follow-up teams generate the risk profile for each child, which will be based on modelling for approximately 3,000 children born very preterm. It is recommended that follow-up teams also take into consideration parental concerns, family circumstances and other health issues when determining a child's risk profile. Ultimately it is at the surveillance team’s discretion how to classify level of risk, and if a digital prediction tool Is not available or appropriate, clinicians can make their judgement based on all available clinical and developmental information they have on the child including developmental assessments at 2-years of age.”
Parent or carer of a child born very preterm #1	This is such a wonderful project. My extreme Premmie twins were born at 27 weeks. We are in a rural area and felt very isolated when we returned home. Thankfully we had a great Paediatrician to support us.	It is very important that all children born very preterm are able to access high quality surveillance, regardless of where they reside and their family circumstances. This was very much a guiding principle of the Model of Care.

Full feedback and responses

Table 1. (contined)

Respondent	Feedback received	Response
	I feel it is very important to monitor until at least the age of 4. I also believe the parents could benefit greatly from mental health support. Especially in the first 12 months.	We agree. The Working Group focused on the 2 to 4 year age period as that was felt to be neglected, but we discussed the importance of surveillance before and after this period. The mental health of parents was a major topic in the Working Group meetings, and on page 17 of the report parent screening for mental health difficulties is recommended.
Parent or carer of a child born very preterm #2	The SurPre model of care sounds like a fantastic initiative for children born prematurely. The importance of helping these children with development is being addressed and by assessing and screening these children to help families know and what they can do to help their children with developmental aspects before school and even through school would be a huge benefit	Thank you for your comment.
	The model of care has some very important principles, and each is very important. Continuity of care as well as effective communication and access are very important for families.	Thank you for your comment.
	Rural struggles are a huge issue across all health care areas. By addressing and reaching out to rural areas is critical. By offering telehealth and support to these children even if they were able to travel for certain assessments from time to time would be very beneficial to those who live rurally or remote.	Thank you for your comment. Our stakeholder consultations and literature review also highlighted how living in regional or rural areas is a barrier in accessing health services. The use of telehealth services is one option at alleviating this.
Parent or carer of a child born very preterm #3	This could mention that children in this bracket are eligible for financial assistance from the NDIS, which may help families who don't seek allied health treatment due to exorbitant cost. I was unaware about the developmental requirements pathway because my child is not clinically 'disabled', and no one mentioned it to me.	While the NDIS was discussed during the Working Group meetings, no formal recommendations were made as the focus of the Model of Care was on surveillance rather than intervention services. However, it would be expected that the surveillance team discusses the NDIS with families of potentially eligible children.
	I really like and appreciate the focus on parent and family mental health and treatment access. Thank you.	Thank you for your comment.

1. Orton J, Tripathi T, Anderson PJ, Boyd RN, Doyle LW, Spittle AJ (2024) Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Review, (CD005495), https://doi.org/10.1002/14651858.CD005495.pub52.
2. Spencer-Smith MM, Spittle AJ, Doyle LW, Lee KJ, Lorefice L, Suetin A, Pascoe L, Anderson PJ. (2012). Long-term benefits of home-based preventive care for preterm infants: a randomized trial. Pediatrics, 130, 1-8.