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Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm

Public Consultation Submission Summary

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1. PUBLIC CONSULTATION PROCESS

The draft *Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm* and associated Administrative and Technical Reports were made available for download on the Newborn Medicine Centre for Research Excellence (CRE) website from 21 August until 13 October.

The Newborn Medicine CRE website contained instructions for making a submission to provide feedback on the guideline. In line with the National Health and Medical Research Council recommendations a 30 day period was originally chosen to allow individuals and organisations to prepare submissions. The deadline was then extended until the 13 October due to a delay in advertising being published. Submission was made by a REDCap survey or by email to the project officer.

The following key stakeholders were notified about public consultation via email:

- Guideline Development Group members, with an invitation to forward to interested parties.
- NHMRC clinical guidelines department
- Commonwealth and state health departments
- Consumer organisations including Miracle Babies Foundation, Life's Little Treasures and Tiny Sparks WA
- Key colleagues of the steering committee
- Relevant professional organisations

In addition, the draft guideline release and public consultation process were advertised in the following ways on and following 21 August 2021:

- Email to individuals who attended the Perinatal Society of Australia and New Zealand (PSANZ) breakfast session dedicated to the preterm follow-up guideline.
- Social media posts on Facebook and Twitter
- Newborn Medicine CRE website news post
- Email to individuals on the Newborn Medicine CRE email distribution list

At the conclusion of the consultation period, the draft guideline had been downloaded 36 times and the social media posts reached a total of 459 people of Facebook and 764 impressions on twitter. In total, 20 submissions had been received from a range of respondents, including state government departments, public clinical service organisations, client and advocacy groups and individuals. Five Individuals and 14 Organisations provided feedback.

One submission remained incomplete and after attempting to contact the respondent on multiple occasions was removed from the received feedback. Overall, the feedback was mostly positive, and many helpful suggestions were received as to how to improve on the draft guideline.

Suggestions were then reviewed and discussed by the guideline steering committee and additional members of the guideline working group when appropriate. Amendments were then made to the

structure and content of the guideline. These amendments were then integrated into the second draft of the guideline and associated documents.

This Public Consultation Submission Summary was prepared to outline the amendments made to the draft guideline and the steering committee's response to each submission. Responses included description of changes made to the guideline or associated documents, rationale for not making changes to the submission or a statement that the submission was beyond the scope of the guideline.

2. STRUCTURE OF THIS DOCUMENT

Each submission received during public consultation has been reproduced in Chapter 4. Submissions were divided into three groups: general feedback, feedback on recommendations and feedback on additional evidence. Submissions have been deidentified and divided into separate feedback items where applicable. Each feedback item is paired with an individual response form the guideline steering committee. Individual feedback items have been presented to allow them to be read independently, therefore there may be repetition in responses.

Feedback responses may have been reformatted and duplication edited, meaning feedback presented may differ slightly from the original submission.

The amendments described below were made to the first draft of the guideline. These amendments were incorporated into the second draft of the guideline and are based on feedback received during the public consultation period.

3. OVERVIEW OF MAJOR AMENDMENTS

3.1 Aboriginal and Torres Strait Islander Peoples

Feedback was received during public consultation that the guideline required greater consideration of issues relevant to Aboriginal and Torres Strait Islander Peoples. In response to this feedback, in conjunction with Tamara Porter, a member of our guideline working group, revisions occurred in three key areas of the guideline; Considerations of issues relevant to Aboriginal and Torres Strait Islander peoples, Follow-up Care after Very Preterm Birth and Supporting Children Born Very Preterm to Transition Successfully to Formal Schooling. Further information can be found in Section 4. Submissions and Corresponding Responses.

3.2 Predictive and prognostic tools

Several respondents requested further clarification of the tools recommended in the previously titled: Clinical Practice Point: Commonly used measurement options. In response to this feedback the table has been moved to Appendix 6, retitled: *Clinical Practice Point: predictive and prognostic tools* and further clarification of the objection of this clinical practice point provided.

3.3 Implementation

Feedback was received about concerns regarding implementation and operationalisation of the recommendations provided in the guideline. In response to these comments, a detailed dissemination and implementation plan was developed after public consultation that focuses on partnering with consumer organisations to assist with implementation of the guidelines across the many different healthcare landscapes across Australia. No amendment was made to the guideline document in response to this feedback.

4. SUBMISSIONS AND CORRESPONDING RESPONSES

4.1 General Feedback

Respondent	Feedback received	Comments/Actions taken by the guideline team
Organisation [1]	Kudos to the steering committee and support groups for pulling off such a massive and important guideline.	Thank you for providing this information. No amendment is required in response to this comment.
	Among the stakeholder groups, it will be important to add social work department as well since ACE (children under CPFS care) are a high-risk population.	Thank you for your comment. Social work was not specifically excluded from the stakeholder groups represented on the Guideline Development Group. The listed stakeholder groups represent those professions of members of the Guideline Development Group who volunteered their time. The guideline team acknowledges that social work is an important profession likely to be included in the follow-up of children born very preterm, depending on the needs of families.
	Also, I could not see any information about CALD community advisor or representative.	Thank you for your comment. The Guideline Development Group included Lucy Meldrum, the practice leader of foundation house, the Victorian Foundation for Survivors of Torture whose work is a specialist refugee trauma agency supporting survivors of torture and other traumatic events who provided her perspectives during the guideline development process.
	What questionnaires or assessments can be done for school readiness? Here at the 5YO visit, we check if the child can write numbers and their name and identify letters/ alphabets, is any centre across ANZNN doing WRAT?	Thank you for your comment. Accurate information about which assessments are being used across the ANZNN is not currently available. Evaluation of specific predictive and prognostic tools was outside the scope of this guideline. Table 11 (Previously Table 4) details some tools as a starting point for services to select tools that might best meet the needs of the service, clinicians available and families involved for a particular developmental domain.

Respondent	Feedback received	Comments/Actions taken by the guideline team
	Given the depth of the guideline it seems imperative to have a MDT approach (feeding, sleep, parental mental health, QOL), how do we intend to make this pragmatic as currently we are staffed only for a clinical psychologist and pediatrician for a 5 YO. Would you envision state/ federal governments funding such initiatives?	Thank you for your comment. The guideline chose to take the perspective of the individual and as such, economic evaluation was not considered as part of the guideline. The comment will be used to inform the development of our dissemination and implementation plan.
	One of my senior colleagues published about 'voice' abnormalities in preterm born children, although majority do well, we do see airway issues in micro- prems (24 weeks and below) following SGS, laryngomalacia etc. Should that be included?	The Guideline Development Group anticipates that airway issues, including those affecting "voice" would be assessed under general health (including respiratory) at all recommended follow-up timepoints. It is anticipated that complex medical conditions would then have independent follow-up pathways organised by treating professionals.
	Also in addition to 'vision' only (acuity at this point or presence of refractory error), we should include some sort of 'colour vision' assessment at 5 YO as we have now seen a few children with neonatal ROP present with impaired colour differentiation irrespective of treatment in the neonatal period.	The Guideline Development Group acknowledges the fact that children may have colour vision issues. The recommendations provided are to cater to all very preterm children. The Guideline Development Group does not believe there is enough evidence to support colour vision testing in all VP infants at 5 years of age.
Organisation [2]	Introduction, pg. 2 Should the included email address be Jeanie's MCRI email address	The email address included in the guideline is preferred by Professor Cheong.
	Glossary, pg. 5 Recommend consistency with capitalisation of glossary terms	Amended
	Glossary, pg.5 Recommend use of corticosteroid versus steroid in description of antenatal steroids.	Amended
	Glossary, pg. 6 Unnecessary capitalisation of 'Ambiguity' in description of language.	Amended

Respondent	Feedback received	Comments/Actions taken by the guideline team
	Glossary, pg. 6 Recommend revising description of Necrotising Enterocolitis. Currently very specific pathology described.	Thank you for your comment. The description of Necrotising enterocolitis has been amended to "A disease of the intestinal tract, that typically affects preterm children, in which the tissue lining the intestine becomes inflamed and can die."
	Glossary, pg. 6 Recommend removing definition of periventricular leukomalacia as already described in brain injury.	Thank you for your comment. Periventricular leukomalacia and intraventricular haemorrhage condensed under brain injury definition as suggested.
	Glossary, pg. 6 Recommend use of corticosteroid versus steroid in description of postnatal steroids.	Amended
	Glossary, pg. 7 Space needed in birth weight as this is two words.	Amended
	Abbreviations, pg. 8 BW, recommend changing abbreviation to birth weight.	Amended
	Abbreviations, pg. 10 Y, consider decision to include Y.	Thank you for your comment. Y has been removed from abbreviations list however added to bottom of recommendations table for clarity.
	From the Chairs, pg. 11 Funny font on 'The G' in the third paragraph.	Amended
	From the Chairs, pg. 11 'All GDG members had no identified or undeclared conflicts of interest.' Recommend changing to 'declared conflicts of interest' as how would you know if they were undeclared?	Amended
	From the Chairs, pg. 11 Remove ',' after Samuel Axford as unnecessary. Correct misspelling of Burnett.	Amended

Respondent	Feedback received	Comments/Actions taken by the guideline team
Organisation [3]	I am interested in feasibility and implementation of the recommendation for VP specific care for VP living regionally or across the border into NSW. Whose responsibility will it be given many VP pass from NICU to regional SCN before going home, the NICU or step down SCN? We are able to provide some things but not all in our regional centre and associated services, is this guideline being shared with funding bodies like the department of health to guide implementation? I understand the first step is development of a guideline and my questions may be out of your scope. Overall, they seem very sensible recommendations.	Thank you for your comment. The guideline recommends that follow-up planning commences in the NICU and that an appropriate follow-up service is provided with a formal handover. The NICU would not be responsible for delivering that follow-up care. In the example given, follow-up planning would commence in the NICU. A text change in the recommendation 1: clinical practice points, has been changed to improve emphasis on this point. "Children born very preterm, and their caregivers should have post discharge follow-up care <u>planning</u> initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible)." The draft guideline has been provided to the Department of Health. When officially published, a dissemination and implementation plan will also be provided to the Department of Health.
Individual [4]	Congratulations on this initiative. Our twins (25wks) spent 14 weeks in NICU and then many post NICU hospital stays. It had a lasting, traumatic impact, even though we've had a successful outcome. Because our twins were born extremely prem, we had significant follow-up, but it would have been much more effective had we known that hospital stays post NICU were significantly likely, as we had multiple trips to emergency for bronchiolitis/ croup. Our son was in a general hospital for 6 days a couple of months after NICU, but their nurses/ doctors didn't seem to understand his illness but wouldn't release us from hospital. My daughter "crashed" post-tonsillectomy when a recovery nurse gave her morphine. Her O2 levels dropped quickly – I didn't panic - her O2 levels wavered significantly during NICU, but the nurse had not seen this type of reaction. The Anaesthetic consultant came out of surgery and advised the nurses to "listen to mum, she's telling you that her daughter's extremely prem".	Thank you for your comment. This comment has been noted for dissemination/implementation planning.

Respondent	Feedback received	Comments/Actions taken by the guideline team
	A big challenge post NICU is that within the NICU "bubble" your infant has such close monitoring, when you are discharged, you cannot expect that from other hospitals (e.g., ED). These guidelines will be most effective if it helps parents to understand how they need to advocate for their child if/ when they are unwell. This guideline should be provided to every ED nurse and doctor, to ensure they recognise the significant likelihood that a VP or EP child will present differently to a non-prem child.	
Organisation [5]	The document is comprehensive, well written and evidence based – this organisation feels it will be a very useful guide to help further develop follow up services and improve existing services across the state.	Thank you for providing this information. No amendment is required in response to this comment.
	The schedule recommendations will be challenging to implement with current funding and staffing in both our tertiary centre and regional and rural referral centres, however, will be a very useful tool to help advocate for improvements to these services.	No action needed and noted for dissemination/implementation planning.
	It will be challenging for the post discharge follow up care to be initiated by the tertiary centre when the patient has been transferred to centres many hours flight or drive away from the tertiary centre. It may be possible to guide follow up of schedule recommendations closer to home (where local services are able to provide this care).	The guideline recommends follow-up planning commences in the NICU with handover to appropriate services. Follow-up care is not expected to be initiated or delivered by the NICU. Implementation will be influenced by the needs, priorities and concerns of each individual child and caregivers and will likely to be different across healthcare services.
		A text change in the recommendation 1: clinical practice points, has been changed to improve emphasis on this point.
		"Children born very preterm, and their caregivers should have post discharge follow-up care <u>planning</u> initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible)."

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		Comment has been noted for dissemination/implementation planning.
Organisation [6]	The recommendations made by The Guideline Development Group (GDG) recommendation on the minimum standards required for follow-up of children born preterm will be of value to all those born very preterm, their families, and all who provide care and support to them, and that it will spark research and implementation activities to promote evidence-based recommendations.	Thank you for providing this information. No amendment is required in response to this comment.
	 However, specific follow-up services for children born very preterm vary considerably across Australia. At the moment, most NICUs in Australia do not have formal follow up process for infants >28 weeks GA at birth. Primary concern will be recommending the same follow up plan for all very premature babies (32 weeks or less). I request GDG to consider stratifying the follow up plan according to their risk factors. For example, ex-29 to 32 weekers could have their follow up plan more based on primary health encounters with screening questionnaires and then referral and assessment at G&D clinics at specific ages only if their screening tools, questionnaires, risk factors (and resilience factors) are considered concerning. Then use the current recommended follow up plan for ex-28 weekers or less. 	Thank you for your comment. As many children born very preterm and their families exhibit multiple risk and resilience factors, the Guideline Development Group felt it inappropriate to stratify care to those based on GA alone, with concerns that children born later would be missed in their follow-up. Services were instead recommended to consider their approach to delivering follow-up for children based on families' preferences, clinical needs, early assessment findings and other relevant factors. It is likely that prior assessments will identify children and families with greatest needs and allow needs-based adjustments, bearing in mind that surveillance for all is recommended to identify emerging difficulties. Modality options may include face to face, telehealth or a hybrid (e.g., telehealth contacts facilitated with a local healthcare professional) based on families' preferences, clinical needs, and any other relevant factors.
Organisation [7]	The guidelines indicate health equity is likely to improve as a consequence of their publication (page 55), despite a lack of evidence (as highlighted in the guidelines themselves). Given the guidelines give almost no specific advice on how inequities might be overcome (in fact, the document specifically	Thank you for your comment. Additional information has been added to the section 'Considerations of issues relevant to Aboriginal and Torres Strait Islander Peoples' on page 19 including reference to the National Agreement on Closing the Gap and the Four Priority
	acknowledges on page 22 that "(s)eparate recommendations for groups with additional needs are not detailed in the guideline"), it is difficult to agree with the conclusion that these guidelines will improve equity.	Reforms. Additional information includes: "These considerations will align with the National Agreement on closing the gap and the four priority

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		reforms. Practitioners should ensure collaboration with Aboriginal and Torres Strait Islander Health practitioners, health workers, and liaisons, as well as local/national Aboriginal Community Controlled Health Organisations (ACCHOs) to ensure a culturally safe approach to care [5]. Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6, 7]."
	The decision to omit any specific advice relating to Aboriginal and Torres Strait Islander babies and families (page 22) is a missed opportunity to redress inequities. If these guidelines are to be considered as relevant to health service providers, policy makers and funding bodies (as outlined in the first paragraphs of the Introduction on page 19), then the importance of the National Agreement on Closing the Gap and its Priority Reforms cannot be overstated. These Reforms highlight the need for government and mainstream organisations to respond to specific and place-based needs of Aboriginal and Torres Strait Islander communities, empower the community-controlled sector and transform their processes and services to redress health inequities faced by these communities. As such, the Priority Reforms should be added referenced in these guidelines.	Thank you for your comment. Additional information has been added to the section three key areas of the guideline including 'Considerations of issues relevant to Aboriginal and Torres Strait Islander Peoples' on page 19 with reference to the National Agreement on Closing the Gap and the Four Priority Reforms. Additional information includes: <i>"These considerations will align with</i> <i>the National Agreement on closing the gap and the four priority</i> <i>reforms. Practitioners should ensure collaboration with Aboriginal</i> <i>and Torres Strait Islander Health practitioners, health workers, and</i> <i>liaisons, as well as local/national Aboriginal Community Controlled</i> <i>Health Organisations (ACCHOs) to ensure a culturally safe approach</i> <i>to care [5]. Culturally safe and appropriate care should be prioritised</i> <i>in the Aboriginal and Torres Strait Islander population, especially</i> <i>those with added complexities such as living in remote communities</i> <i>whose access to care is already reduced [6, 7]."</i>
	We have been unable to identify any reference to or consultation with the community-controlled sector in the development of these guidelines. This is disappointing given the paramount importance of Aboriginal and Torres Strait Islander partnership as outlined in Priority Reform 1, and the inequitable burden of prematurity experienced.	Thank you for your comment. The guideline development team conducted a targeted search to ensure ATSI representation was part of the Guideline Development Group. The Guideline Development Group was fortunate to have Tamara Porter and Tracey Stephens as part of the team during development to provide their perspectives. The project officer reached out to NACCHO in early 2022 to

Respondent	Feedback received	Comments/Actions taken by the guideline team
		collaborate on this guideline however was unable to establish a working partnership. The guideline was sent to NACCHO during both public consultation periods for this guideline for comment/feedback.
Individual [9]	In several places, the Guideline references that difficulties in children born Very Preterm may emerge later in development. The references are inconsistent and variously refer to 'later in the preschool years', 'different points in children's development', 'later into childhood' or 'later in development'. There should be greater consistency in the text around the possibility of both health and development issues not becoming evident until later in life, even into adulthood. This possibility should be explicit and clear, particularly in the plain language summary which refers to 'Some difficulties present early in life and others later in the preschool years'.	Thank you for your comment. I have amended language for consistency; however, it should be noted that the guideline is specifically targeting the period between birth and starting of formal schooling and is unable to make recommendations for children after commencement of formal schooling.
	The Clinical Practice Points advise 'clinicians to offer more support if considered necessary'. Given the possibility of health or development issues not manifesting until later in life, clinicians should be advised to maintain actively open-minded thinking when assessing children born VP, regardless of previous follow up results. It is important for families to ensure that health providers are aware that their child was born VP.	Thank you for your comment. The clinical practice points support clinicians to rely on their clinical judgment and offer more support as they consider appropriate. This would include services/supports/interventions they feel are appropriate regardless of previous follow-up results. Footnote has been amended below the recommendations schedule to remove reference to last contact and now reads <i>"a review if parental concerns or clinical need"</i>
	What is the mechanism for clinicians and families to report back so that future Guidelines can be amended? The lack of a feedback mechanism shifts reliance onto longitudinal studies and research that may or may not be funded and greatly prolongs improvements, safety and change. Identifying and responding to needs more quickly improves access to care and generates consistent information to plan and deliver care. The University of Wollongong's Palliative Care Outcomes Collaboration is a model that could be considered for follow-up of children born VP.	 Thank you for your comment. As part of our dissemination and implementation plan our team will be partnering with consumer organisations. As part of future planning, we recognise that it would be ideal to have a data collection mechanism, with feedback from those with lived experience, clinicians and services to assess acceptability and value of the recommended approach. There is an Australian/New Zealand neonatal network that could be used to enhance data collection, alongside the consumer group engagement. We will also review the outcomes collaboration that you have recommended to

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		assess if elements of that approach would enhance existing data collection opportunities for neonates. The Guideline Development Group will be asked to reconvene in 5 years to review and update the guideline as required. If additional resources are found and there is an increased need/demand from consumer organisations our team would be happy to reconvene at an earlier date.
Organisation	Thanks for opportunity to review this excellent document. It is noted that it is	Thank you for your comment. The Guideline Development Group
[11]	evidence based and a comprehensive resource with appropriate language for both health care and other professionals. The documents outline a very robust guideline development process. However,	thought it essential to not list individual professions for the conduct of each timepoint follow-up review due to the varying nature of available services across Australia. Rather, the decision was made to
	while the document focusses on evidenced based recommendations for post discharge health and developmental surveillance for this cohort of newborns, it does not appear to make recommendations as to what groups might provide post discharge follow up at the various stages of the surveillance matrix from the first week after discharge through to 4-5 years of age. The Department of Health notes the specialized nature of the follow up and assessment required and that the discharging Neonatal Intensive Care Unit would likely coordinate follow up. While community practitioners are mentioned, it is not clear:	recommend that any clinicians (including general practitioners) who are appropriately trained could assess the priority areas listed in these guidelines. This training will be dependent on the needs of the clinical services and the families under their care. No amendment was made in response to this comment.
	Which professions	
	What level of additional training may be required	
	• Any variations in the required specialist expertise as the child ages developmentally.	
	It is suggested to consider the role for the usual family General Practitioner (GP) in post discharge care, especially as they will likely become the ongoing medical carer for these children after the age of 5 years. So inclusion in a shared surveillance model, perhaps entering the post discharge surveillance	

Respondent	Feedback received	Comments/Actions taken by the guideline team
	matrix at a defined point in the matrix would facilitate continuity of care. The direct engagement of GPs in a shared surveillance model becomes even more necessary where the child returns to remote or rural Western Australia which covers a third of the WA population.	
[12]implementing a structured schedule which should be universally implemented to all babies born very preterm.of health p workforce, negative of structured, preterm-specific follow up care such as socio-economic status and remoteness, it does not examine the evidence pertaining to 'why' some of these particular factors negatively impact on outcomes. For example, if issues such as the lack of an appropriate skilled public health workforce in rural/remote locations is contributing to negative outcomes, this could beof health p workforce, negative of have inclusion workforce, negative of those particular factors negatively impact on outcomes. For example, if issues such as the lack of an appropriate skilled public health workforce in rural/remote locations is contributing to negative outcomes, this could beof health p workforce, negative of have inclusion skilled staff follow-up	Thank you for your comment. Although we know there is a shortage of health professionals across the Australian public healthcare workforce, we do not know whether this shortage is directly linked to negative outcomes for children born very preterm and as such we have included your suggestion in our future research priorities section. <i>"Understanding impact, <u>resources required, including appropriately</u> <u>skilled staff</u> and cost-effectiveness of structured, preterm specific follow-up programs will require significant future research using a structured approach."</i>	
	The guideline identifies First Nations families as a group who may have 'additional or different needs'. However, the guideline does not identify any factors pertaining to why this group experience disparity, such as the culturally acceptability and accessibility of services, the lack of culturally appropriate assessment tools, or a higher proportion of First Nations people residing in rural and remote locations. The guideline also doesn't identify evidence-based strategies which may address negative outcomes experienced by First Nations people, such as implementing cultural safety in clinical practice and targeted financial investment into the development of culturally safe resources and care. If evidence is not available pertaining to how to improve outcomes for 'at risk'	Thank you for your comment. The guideline acknowledges that there are several groups who have additional or different needs and that these groups may be less likely to access follow-up programs on page 18 under the heading <i>Consideration of issues relevant to children and families that may have additional or different needs</i> . The reasons for these additional or different needs are not described for these groups however it is noted that services should ensure that adequate resources are available to engage groups less likely to access follow-up care.

Respondent	Feedback received	Comments/Actions taken by the guideline team
	populations including First Nations people, this too could be added to the future research priorities on page 65.	Additional information has also been included in the section Consideration of issues relevant to Aboriginal and Torres Strait Islander peoples on page 19.
		"Important considerations for implementation of the guideline for Aboriginal and Torres Strait Islander people will be considered in the development of the Dissemination and Implementation Plan. These considerations will align with the National Agreement on closing the gap and the four priority reforms. Practitioners should also ensure collaboration with Aboriginal and Torres Strait Islander Health practitioners, health workers, and liaisons, as well as local/national Aboriginal Community Controlled organisations (ACCHO's) to ensure a culturally safe approach to care [5]. Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6, 7]."
Individual [13]	 I was the Foundation President of the ASDP (formerly NBPSA). This is an organisation of more than 800 doctors, mostly paediatricians, with a specialist interest in child development. Whilst I do not speak now on behalf of our organisation, I do have a continuing role in professional practice development and education. I have one comment only – what I see as an important omission. There is ample evidence defining 'risk factors' for developmental problems post premature birth. To my understanding this comes in two phases – more serious problems in the preschool years, and more subtle problems in school years (e.g., Executive Function). On the basis of this evidence, I consider it appropriate to recommend early intervention of some kind for those children who are at risk. In our clinical experience, parents who learn to 'read' the signs of their infant's state organisation, who structure posture, attention control, emotional control, who 	Thank you for your suggestion. The importance of early intervention is highlighted throughout the guideline in the Context and Background and the Current Landscape of Follow-up Care in Very Preterm Birth sections on page 15 and 37 respectively. The goal of structured follow-up is to detect children with developmental problems at an early age, maximising the opportunity to provide services at a time when early intervention is most effective. We agree that it would be ideal to recommend interventions, including those for children prior to difficulties and needs being identified. However, intervention recommendations were outside the scope of this guideline. Instead, we have included a goal to encourage parents and clinicians to have early discussions about interventions and other measures to optimise outcome.

Respondent	Feedback received	Comments/Actions taken by the guideline team
	 manage the structure of household life and so on, all of these can make a substantial difference. Specifically, this work can start BEFORE a problem is detected, for children at higher than background risk. There is an evidence basis for this recommendation – e.g. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6888619/ Failure to recommend structured EI – oriented parenting for those children 'at risk' I would consider an opportunity lost 	
Organisation [14]	This comprehensive document highlights the importance of early detection and guidance for implementation for follow-up for very Preterm Infants. A guide for parents to accompany these recommendations may support the journey and reduce barriers to access services - some screening / anticipatory guidance may be undertaken in a Universal Service with more specialised assessments in Tertiary Centres. Delineation of universal and specialist follow- up roles and responsibilities would be helpful.	Thank you for your comment. The suggestion of a guide for parents has been noted as a possible future reference piece to be developed as part of the dissemination and implementation plan. Follow-up should be completed by appropriately trained clinicians with referrals to other specialists as indicated by assessment. This guideline does not make recommendations about review by specialists. Many complex conditions will have specialist review pathways outside of the recommendations provided in this guideline. Implementation will vary across areas of Australia and this guideline does not necessarily recommend children return to the tertiary centre for follow-up if it is not indicated.
	Although the guideline recommends equitable follow-up it does not recommend a tiered approach to follow up for children born very preterm early in the document. Later in the document however, it states stratification based on previous clinical findings (including the use of screening questionnaires). These need to be visible within the consensus-based follow-up table summary at the beginning of the document as this is what will be read. The document specifies use of developmental and cognitive assessment tools	Thank you for your comment. The guideline recommends that all children born <32 weeks have access to follow-up (for equity). A tiered approach would introduce inequity. The structured follow-up recommended has flexibility for mode of follow-up (community vs tertiary care, face to face vs. telehealth) depending on the individual circumstances of the families. The decision was made not to move Table 4 (now Table 11) to the executive summary as suggested as this is not the main focus of the guideline. The measurement options provided are not intended to be
	rather than screening tools. Not all infants between 28-32 wks gestation would	comprehensive, nor are we suggesting that these are the only tools

Respondent	Feedback received	Comments/Actions taken by the guideline team
	require or benefit from this. This significantly reduces accessibility for regional	that could be used to guide follow-up of children born very preterm.
	and remote families and primary care services, as access to psychology would	These measurement options should be adapted to achieve the same
	be required for formal cognitive assessment. Families would be potentially	goals based on the experience, expertise of the available assessors
	travelling hundreds of kms for an assessment where there is no clinical indication. Low/below average scores may induce stress or anxiety for the	and healthcare setting
	family but not be helpful. Screening first would be most appropriate and then formal assessment if indicated.	The description of the predictive and prognostic tools (Appendix 6) has been amended to reflect this.
		"The evidence investigating specific tools was outside the scope of this guideline, therefore the GDG has developed the below clinical practice points based on the GDG's experience only. This table is not intended to be comprehensive or the only tools that could be used to guide follow-up of children born very preterm. It is intended as a starting point from which clinicians/services should consider tools to achieve the same goals based on the experience and expertise of available staff." Page 91
	There appears to have been no consultation with either RACP or NBPSA.	Thank you for your comment. As you have noted, there was no direct consultation with RACP or NBPSA however our guideline was shared widely during public consultation including to each state and territory and commonwealth health departments and feedback welcomed from many professional organisations as well as individual responses.
Individual	During the time my son was in Townsville NICU (26 weeks) in early 2015, we	Thank you for sharing your experience. We hope this guideline will
[15]	 were extremely fortunate to participate in the Family Integrated Care Trial (FI-Care). Participating in this trial, during what was without doubt the most stressful and difficult time in our lives, was nothing short of transformative. When you feel as though you have failed your child and have nothing meaningful to contribute to their survival, FI-Care empowers caregivers by educating them, giving them a voice and an active role to play in their child's medical care. FI-Care strengthens bonds and increases parental confidence, undoubtedly significantly improving well-being and positive outcomes for both 	improve care for all families with children born very preterm and help advocate for support for programs like you have described. No amendment is required in response to this comment.

Respondent	Feedback received	Comments/Actions taken by the guideline team
	children and families. The value of FI-Care cannot be overestimated, and every child and family should not be denied and deserve the opportunity to engage in this vital and consequential program.	
Individual [16]	- The recommendation table is not that clear. What does the '+' mean? Why are some ages greyed out?	The + indicates the need for review at the indicated timepoint for the indicated domain. The timepoints where follow-up is recommended if parental concerns of clinical need for follow-up from last contact. The reason for greyed out columns has been added to the footnote of the table.
	- pg 21, 1.4: "if gestational age is unclear and their caregivers." This sentence is unfinished.	Amended. Sentence now reads "This guideline is relevant to all children born very preterm at <32 weeks' gestation or with birthweight <1500 g if gestation age is unclear."
	- Tables: It would help visually if the headings of each column are in bold to differentiate from the rest of the information	Headings of columns made bold consistently throughout document.
Organisation [17]	Good information regarding Very Preterm babies and the associated challenges they face	Thank you for providing this information. No amendment is required in response to this comment.
	The document really doesn't provided what is 'follow-up' care – with each jurisdiction having its own Key Ages and Stage visits, this could be useful if there is an age point that an individual State/Territory doesn't offer (Vic and NT do) i.e. does everyone have occasions of service at these age points already?	Thank you for your comment. As can be seen in <i>Follow-up care after</i> <i>very preterm birth – The current landscape of follow-up care in</i> <i>Australia</i> section of the guideline, pre-term specific follow-up varies substantially across Australia. It is our hope that the recommendations provided in this guideline could be adapted into already existing pre-term specific follow-up programs that may already exist in certain states. No amendment is required in response to this comment.
	It doesn't touch on what is one of the major impediment to outcome successes for these babies i.e. VP babies (as are SGA) are being discharged too early at weights that are suboptimal	Thank you for your comment. The guideline does not focus on the acute hospital care of very preterm infants but aims to enhance the continuity of care between hospital inpatient services and post-discharge follow-up. It is our hope that the recommendations assist in the follow-up care for very preterm babies that are small for

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		gestational care. No amendment has been made in response to this comment.
	We note one MCFH representative, Helen Lees from the Municipal Association of Victoria (MAV), was a voting member of the Guideline Development Group (GDG)	Thank you for providing this information. No amendment is required in response to this comment.
	States "Post discharge care may involve many healthcare professionals and different healthcare services, including hospitals, community practitioners, and universal services (e.g., Maternal Child Health Service). Communication and coordination are essential to maximise efficiency, reduce duplication of effort, and minimise the burden to families. Appointing a lead clinical contact within a multi-disciplinary team may facilitate this." How is this work to be funded???	Thank you for your comment. A cost analysis was outside the scope of this guideline, however your comment has been noted for the development of the implementation and dissemination plan which will be released alongside the published guideline.
	Talks about 'providing appropriate management within the scope of the service or health professional, and referring on for additional support, intervention, or investigation as needed.' – with waiting lists being out of control, how will this be managed?	Thank you for your comment. Your comment has been noted for the development of the implementation and dissemination plan which will be released alongside the published guideline. Although, the guideline development team recognises the presence of waiting lists, the recommendations are based on evidence and consensus regarding best practice.
	GP's are often a barrier to MCFHN concerns being progressed - without capacity for direct referral this is a 'crack' that babies often fall into	Thank you for your comment. It is our hope that this guideline can be used as an advocacy document for both families and clinicians to assist in the progress of care.
	it seems to rely on existing services which vary greatly around Australia. There is no clear message about child and family health nursing services or connection to GPs. Parents of preterm babies tend to get caught up in medical models of care which may be appropriate but do not give them additional social and emotional support.	Thank you for your comment. Our guideline team felt that naming individual professions would limit the implementation of guideline recommendations and chose instead to focus on professionals with the appropriate skills and training to be involved in the preterm specific follow-up of these children. It is anticipated that maternal and child health nurses and general practitioners with the skills to deliver preterm specific follow-up care will be involved in this care around Australia.

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	Having a discharge planner from the treating hospital that kept in contact with the family in those first week after discharge might be useful. Just making sure they are connected to appropriate services It is still incredibly important for the infants to be still linked to their local CFHN and GPS.	Thank you for your comment. The Guideline Development Group agrees that appropriate follow-up is essential, so families are connected to the appropriate services. The guideline specifies this should be initiated by the treating NICU and is highlighted in the clinical practice points "Children born very preterm, and their caregivers should have post discharge follow-up care initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible)." Pg. 12
	MCFHN are an important link as have primary health care/ family focused lens, adding support, networking families into community, support positive parent- infant interaction for benefiting long-term growth and development trajectory.	Thank you for your comment. The guideline acknowledges the importance of primary care in the follow-up of children born <32 weeks and their families, of which MCHN play an integral role. As with all clinicians involved in children born very preterm, clinicians should be appropriately trained to assess the priority areas recommended in the guideline.
Organisation [18]	The content of the guidelines is good, but the structure and formatting of the document make it difficult to find the necessary information. A more intuitive contents page and greater signposting of information would improve accessibility. Additionally, the layout of the document is unclear, and it is challenging to differentiate chapter numbers from other numerical reference points. We suggest greater signposting of information / a more intuitive contents page.	Thank you for your comment. The table of contents have been amended and the numbering layout changed to make the table of contents more intuitive. The glossary and appendix have been moved to the appendices to ensure readability.
	A large chunk of the document is focused on methods, and this disrupts the flow of the report. Suggest moving to an attachment, to ensure the document focuses on the content of the guidelines. Using both evidence-based recommendations and consensus clinical recommendations may create confusion for the reader, and it may be helpful to rename them to differentiate further.	 Thank you for your comment. The methods included in the guideline are a requirement for approval by the NHMRC. Supplement resources will likely be developed after approval of the guideline including a summary of recommendations which will not include the methodology behind recommendations. The guideline includes consensus clinical recommendations and clinical practice points. This terminology is preferred by the NHMRC.

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		Again, supplement resources will likely be developed including plain language to assist with dissemination and implementation of the guideline.
	Additionally, it would be beneficial to link these guidelines to wider work on early childhood, including the early years strategy and the first 2000 days work. Specifically, there could be links to strategies to support the transition to school.	Thank you for your comment. We acknowledge that wider work has been conducted for the early childhood period. This guideline focuses specifically on work for children born very preterm and their families. It is clear that very preterm children's transition to school may require additional support but should be in keeping with recommendations for all children. No amendment has been made in response to this comment.
	The prevalence and risk of child maltreatment increases when children belong in priority populations (rural and remote, having a disability, First Nations, CALD etc), and when families experience adversities. A suggestion would be to add more periodic check-ups on child and family well-being, especially for priority populations. The current guidelines have a lengthy gap between 24 months to 4-5 years old.	Thank you for your comment. The guideline recommendations include a follow-up at 2.5 years if parental concerns or clinical need. The guideline proposal offers a minimum set of contacts and priorities and services and clinicians should offer more support as they consider appropriate based on individual circumstances. No amendment was made in response to this comment.
Organisation [19]	 General Practitioners (GPs) are the first point of contact for families seeking healthcare and are uniquely placed to form an early social relationship with the child and their family and/or carer. As such, a person's GP is central to providing comprehensive health care across various ages, and life stages, and will play a key role in ensuring children born very preterm continue to receive appropriate follow-up care. It is important that the GP's role in this support and in facilitating shared care arrangements is clearly articulated in the guideline. Similarly, the importance of communication and coordination post-discharge needs to be acknowledged throughout the guideline. The RACGP's Shared Care Model between GP and non-GP specialists for complex chronic conditions position statement provides more information on the importance of having good shared-care models. 	Thank you for your comment. Our team felt that naming individual professions throughout the guideline would limit the ability of the recommendations to be implemented across Australia and instead focused on the skills of individual health professionals to provide preterm specific follow-up care. It is likely the role of GPs in providing preterm-specific care for children born very preterm and their families will vary considerably across different settings in Australia. The intended audience for the guideline has been amended on page 17 to specific primary health care workers including GPs and MCHNs. <i>"The guideline is mainly intended for health professionals and others involved in the support of children born very preterm and their families, such as primary health care workers (e.g. GPs and MCHN), early childhood educators and disability and community service</i>

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	 The Guideline would also benefit from the target audience being clearly identified at the beginning of the document. Recommendation: The guideline clearly articulates the role of the GP in supporting the infant and family and facilitating shared care arrangements for provision of structured follow-up care, consistent with the RACGP's Shared Care Model position statement referenced above. 	workers. We anticipate this guideline will also be used by families with children born very preterm."	
Organisation [20]	The GDG has produced a comprehensive consensus document that provides helpful recommendations for structuring VP infant follow up services.	Thank you for providing this information. No amendment is required in response to this comment.	
	Not all services have capacity/resources for blanket face to face assessment at 24 months and cognitive screening at 4-5 years CA. We suggest prioritisation of face to face assessment at 2 years CA by risk identified in early assessments as well as results of follow up screening. e.g. ASQ or ASQ- TRAK. ASQ had pooled sensitivity of 0.77 and specificity of 0.81 to diagnose any developmental delay, and sensitivity of 0.84 and specificity of 0.77 to diagnose severe developmental delay in children aged 12 to 60 months. (Muthusamy et al. 2022, JAMA) Finding resources for formal cognitive screening at 4-5 years will be problematic for many services and will require additional funding of specialist clinicians. A prioritised model may be more cost effective and practical but there is limited evidence to support inclusion criteria. Parental concern may be a guiding but not necessarily a robust indicator. This may be an area requiring further research.	Thank you for your comment. We agree that there is insufficient evidence to inform a prioritised model for this guideline. The guideline recommendations include clinical practice points that suggest "Services should be flexible in their approach to providing follow-up based on families' preferences, clinical needs, early assessment findings and other relevant factors. Modality options may include face to face, telehealth or hybrid (e.g., telehealth contact facilitated with a local healthcare professional) based on families' preferences, clinical needs, and any other relevant factors". We do not anticipate that all assessments will be provided by a specific preterm service, with options for assessments to be completed by community, education and disability services as appropriate. No amendment has been made in response to this comment.	
	Section 1.5 clearly states this guideline does not address "evaluation of specific tools that could be used for assessment" but it still provides clinical practice points. Including Table 4 implies recommendation to the reader and is therefore out of scope given there has been no formal evaluation by scoping or systematic review. We recommend this section be removed. There are other	Thank you for your comment. Table 11 (previously Table 4) includes a set of predictive and prognostic tools that may assist in individual services selecting the most appropriate tools for use within their respective services. The description of the table has been amended to clarify this and the table has been moved to Appendix 6, as detailed in the major amendments section of this submission's summary. The table is not intended to be comprehensive or the only	

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	scoping, systematic reviews and international consensus statements that cover	tools that could be used to guide follow-up of children born very
	choice of assessment measures for VP infants.	preterm. It is a starting point from which clinicians/services should consider tools to achieve the same goals based on the experience and expertise of available staff.

4.2 Feedback on Recommendations

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Organisation [2]	Guideline	Executive Summary	16	Recommendation 1	Who is it envisaged does this? GP? MCHN? Or not required to be specified?	Clinicians delivering follow-up to children born very preterm should be appropriately trained/upskilled to assess the priority areas listed in these guidelines. It is hoped that these services may be provided in different healthcare services, including hospitals, community practitioners and universal services (e.g. MCHN) based on families' preferences, clinical needs and other relevant factors. No amendment has been made in response to this comment.
	Guideline	Executive Summary	16	Recommendation 1, 24mo CA timepoint	So no range given here? 24-30 months corrected??	The timepoint recommended is 24 months corrected age with a review at 2.5 years if parental concerns or clinical need for follow-up. No amendment has been made in response to this comment.

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	Guideline	Clinical Practice Point: Commonly used measurement options	51	Table 4 – commonly used measurement options – Multiple domains section	Is there ONE preferred tool that should be recommended? Is there ONE preferred tool that should be recommended or ONE in certain circumstances and ANOTHER in other circumstances?	An evaluation of the evidence investigating specific measurement tools was outside of the scope of this guideline. The presented tools are not intended to be comprehensive or the only tools that could be used to guide follow-up of children born very preterm. Measurement options should be adapted to achieve the same goals based on the setting, experience and expertise of available assessors. No amendment has been made in response to this comment.
Organisation [5]	Guideline	Chapter 1. Structured follow up. Consensus based recommendation 1	52	Recommendation Number 4.6	Hammersmith Infant Neurological Examination (HINE) is recommended in bold – however there is no bold timepoint highlighted. It would be helpful to recommend a timepoint (or explain why there is no timepoint recommended for this assessment whereas all other assessments in bold and in this table have a recommended timepoint).	Thank you for your comment. The timepoint 6-12month CA has been bolded in response to your comment based on the clinical experience of members of our Guideline Development Group.
	Guideline	Chapter 1. Structured follow up. Consensus based recommendation 1	48	Recommendation Number 4.6	Regarding; Children born very preterm, and their caregivers should have post discharge follow-up care initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible). Further explanation	Thank you for your comment. Our recommendation suggested planning for follow-up commences in the NICU with the responsibility of the NICU to handover to an appropriate follow-up service. It is not intended that the follow-up be necessarily delivered by

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200111221011					regarding recommendations on what this means / looks like for children from non- metropolitan areas often back transferred vast distances from the tertiary centre prior to discharge would be helpful (especially regarding the early follow up timepoints). The last point on flexibility in approach helps though does not clarify what "initiation" means.	the treating NICU and the delivery of follow-up will depend on several factors including family preferences, clinical needs and other relevant factors and likely vary significantly around the country. A dissemination and implementation plan will be developed alongside the finalised guideline to assist with factors to consider when implementing recommendations. Your comment has been noted for the development of the document.
Organisation [6]	Guideline	Recommendations 1 & 2	13 & 14	Recommendations 1 & 2	Recommendation 1: Structured, preterm- specific post-discharge follow-up care should be offered to children born very preterm and their caregivers Recommendation 2: Structured, preterm- specific follow-up care should be offered to children born very preterm and their caregivers regardless of presence of risk and/or resilience factors. Can the recommendations 1 and 2 be combined together into 1 recommendation, e.g.: Structured, preterm-specific post- discharge follow-up care should be offered to children born very preterm and their	Thank you for your comment. The recommendations have been combined in our Summary of Recommendations Document however remain separate in the guideline document itself to reflect the recommendations made after the two individual systematic reviews of the available evidence.

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					caregivers regardless of presence of risk and/or resilience factors.	
	Guideline	Clinical practice points	15	4 th bullet point	One of the recommendations: "Corrected age should be used when considering a child's growth, health, and development." – The current practice is children are followed up at 5 years of age, not 5 years corrected age. Can GDG provide further clarification on this?	Given the potential life-long effects of being born very preterm, and emerging evidence supporting correction for prematurity into childhood and beyond, the Guideline Development Group felt strongly that children should be followed up based on corrected age rather than chronological age to ensure differences to age-group peers did not facilitate unnecessary referrals or burden to families. Relevant References: van Veen S, Aarnoudse-Moens CSH, et al. Consequences of correcting IQ for prematurity at age 5 years. J Pediatr 2016;173:90–5. Doyle LW, Anderson PJ. Do we need to correct age for prematurity when assessing children? J Pediatr 2016;173:11–12. Wilson-Ching M, Pascoe L, Doyle LW, et al. Effects of correcting for prematurity on cognitive test scores in childhood. J Paediatr Child Health 2014;50:182–8.
						Veldhuizen S, Rodriguez C, Wade TJ, et al. Misclassification due to age grouping

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						in measures of child development. Arch Dis Child 2015;100:220–4.
						No amendment has been made in response to this comment.
	Guideline	Consensus-based Recommendation 1: Follow-up Schedule Recommendations Table	16	Vaccination schedule at 6-week post- discharge and 8-9 months CA	Vaccines are given at the actual age, not corrected age. Can GDG add further clarification on this?	Thank you for your comment. Vaccinations are administered according to chronological age. The follow-up schedule has been amended to reflect this both in the Executive Summary and Chapter 1 recommendations.
	Guideline	Consensus-based Recommendation 1: Follow-up Schedule Recommendations Table	16	Growth	GDG advice is on growth – I assume this is physical growth. Head circumference is not mentioned/recommended in this recommendation.	Thank you for your comment. The guideline recommends a holistic view of physical health including an assessment on growth which may include height and head circumference, directed by the clinical judgement of the individual assessing clinician. No amendment has been made in response to this comment.
	Guideline	1.2 Purpose of the guideline	20		 The following guiding principles are practical, sensible, realistic and achievable: Follow-up care should be family centred, flexible, resource efficient, and consistent. Follow-up should be equitable, culturally safe, and appropriate to each individual 	Thank you for providing this information. No amendment is required in response to this comment.

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					child and family's needs, preferences, and values	
	Guideline	Table 4- Commonly used measurement options	51		Their recommendation on flexible services embracing telehealth or hybrid will improve the follow-up rates, particularly among those who live far away from the follow-up clinics. They recommended any of the following measurement options, including Bayley, Griffiths, Ages and Stages Questionnaire, PARCA-R are suited for formal follow-up assessment. Can GDG provide any guidance on comparison of these tools? For example, currently Bayleys, Griffiths and Wechsler are the only scales formally approved tools for assessment of children.	The guideline does not provide an evaluation of specific tools that could be used for assessment. This is considered outside of the scope of the guideline. This can be found under 1.5 What the guideline does not address, page 17-18. The description of the predictive and prognostic tools (now moved to Appendix 6) has been amended to reflect this. <i>"The evidence investigating specific tools was outside the scope of this guideline, therefore the GDG has developed the below clinical practice points based on the GDG's experience only. This table is not intended to be comprehensive or the only tools that could be used to guide follow-up of children born very preterm. It is intended as a starting point from which clinicians/services should consider tools to achieve the same goals based on the experience and expertise of available staff." Page 91</i>
Organisation	Guideline	1.7 Consideration of issues relevant	22		Aboriginal Community Controlled Health Organisations (ACCHOs) have been shown	Thank you for your comment. Additional information has been added

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[7]		to Aboriginal and Torres Strait Islander Peoples			 to improve health outcomes relating to preterm infants and NACCHO recommends that their presence should be noted in discussing the consideration of issues relevant to children and families that may have additional or different needs. Likewise, the key roles that Aboriginal and Torres Strait Islander Health Workers, Health Practitioners and Hospital Liaison Officers must play in caring for and supporting families experiencing preterm births should be acknowledged. Their role is essential to the delivery of culturally safe care. 	to page 19, Consideration of issues relevant to Aboriginal and Torres Strait Islander Peoples. "These considerations will align with the National Agreement on closing the gap and the four priority reforms. Practitioners should ensure collaboration with Aboriginal and Torres Strait Islander Health practitioners, health workers, and liaisons, as well as local/national Aboriginal Community Controlled Health Organisations (ACCHOs) to ensure a culturally safe approach to care [5]. Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6, 7]."
	Guideline	Background	36		Although data regarding the frequency of very preterm births among Aboriginal and Torres Strait Islander peoples appears to be lacking, there are compelling data relating to the inequitable burden of premature births experienced by Aboriginal and Torres Strait Islander communities which are highly relevant to	Thank you for your comment. The Guideline Development Group acknowledges the inequitable burden of premature births experiences by Aboriginal and Torres Strait Islander communities. Unfortunately, the Guideline Development Group was unable to locate any data regarding the frequency of very preterm births among Aboriginal and Torres Strait Islander

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					the epidemiology of prematurity and birthweight in Australia.	peoples. No amendment has been made in response to this comment.
	Guideline	3.3 Impact (Background)	37		Cultural considerations are not given sufficient consideration or weight in this document. Compelling issues faced by Aboriginal and Torres Strait Islander parents and families (such as institutional racism and the stolen generations) are completely overlooked. This is problematic, especially as families will need to spend prolonged periods of time in environments, they may consider to be culturally unsafe. The decision to exclude specific recommendations relevant to families with specific needs promotes the status quo – which is not working for many families. The National Agreement on Closing the Gap should inform these guidelines.	Thank you for your comment. The section 'Impacts on Parental Wellbeing' on page 37 is discussing physiological medical changes for an infant, rather than a holistic view. However more information has been included in background sections to address your comment. No amendment has been made in response to this comment.
	Guideline	3.4 Follow-up care	40		The vital importance of culturally safe approaches, the role of the ACCHO sector and importance of connecting families with Aboriginal and Torres Strait Islander health professionals and organisations must be acknowledged. As well as recognising "the importance of incorporating a child's positive characteristics, such as their strengths and qualities, into the clinical understanding of	Thank you for your comment. Additional information has been included in this section Follow-up care on page 37. "Aboriginal and Torres Strait Islander families should be linked in with services to support access to ongoing care, through local Aboriginal Cooperation's, Aboriginal Community Controlled Health Organisations, and hospital supports".

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					their situation", so too a greater focus on culture, language and extended family and community is essential. Cultural safety must have a stronger focus in this section.	
	Guideline	3.5	43		Supporting children to transition to schooling will impact on efforts to Close the Gap. All levels of government have committed to new ways of working (through the National Agreement and four priority reforms) and the guidelines have a role to play in raising awareness and helping redress inequities. The importance of culturally safe approaches and linking Aboriginal and Torres Strait Islander families and children with community controlled organisations must be acknowledged.	Thank you for your comment. Additional information has been included in this section on page 41. "The National agreement on closing the gap aims to reduces socio-economic disadvantage on Aboriginal and Torres Strait Islander Australians [5]. Targets 3- 6 focus on ensuring equity in childhood education and health, with an emphasis on Aboriginal children reaching their full potential. For those born very preterm, a culturally safe transition into childcare and school will support ongoing growth and developments of the child."
	Guideline	4.1	45		The Domains outlined in Table 3 do not currently include any consideration of culture or community. Families do not operate in isolation. The broader social and cultural determinants of health need a stronger focus in these guidelines.	Thank you for your comment. The steering committee acknowledges that culture/community is not clearly highlighted in this table however the domains outlined in Table 3 were developed after a period of public consultation and Guideline Development Group voting and underpin the second systematic review of the guideline. No amendment has

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						been made in response to this comment.
	Guideline	4.6	52-53		Measures of parental wellbeing should consider the inclusion of physical risks to health, given recent findings which indicate that mothers who had a preterm birth in Western Australia were at risk of early mortality for decades after giving birth. Would recommend an additional domain that includes a focus on culture and community be considered a key priority. The current domains promote a limited, biomedical perspective that is not inclusive and perpetuates existing inequities.	Thank you for your comment. During the guideline development public consultation was undertaken on the scope and focus of outcomes for children born very preterm and their families. Parental wellbeing outcomes suggested in public consultation focused heavily on parental wellbeing and parenting outcomes. Although the Guideline Development Group acknowledges that parental wellbeing should include the physical risk to health, follow-up of these physical risks may be outside the scope of this guideline and have the potential to be an independent guideline. No amendment has been made in response to this comment.
	Guideline	4.7 Clinical considerations for implementation of the recommendations	55	Recommendation 1	Equity and feasibility: appropriate resourcing of rural and remote child health services is known not to occur equitably and with a greater proportion of the Aboriginal and Torres Strait Islander population (compared with the non- Indigenous population) living in these areas, these populations are likely to be further affected by health inequity if	Thank you for your comment. This section is saying equity factors need to be considered in the implementation of the recommendation that children born very preterm and their caregivers are offered a basis/structure of best practice around follow-up for very preterm infants. No amendment has

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					regular follow-up is required. Remoteness is identified as being a risk factor for reduced access to healthcare within these guidelines.	been made in response to this comment.
	Guideline	Chapter 2 – Risk / Resilience factor recommendations	56	recommendation 2	Culture has repeatedly been identified as contributing to strength and resilience for Aboriginal and Torres Strait Islander people and communities. Whilst there are limited studies specifically relevant to Aboriginal and Torres Strait Islander people, cultural components (such as music, cultural ceremonies) and community-led initiatives have been found to reduce stress responses and improve outcomes.	Thank you for your comment. Recommendation 2 was made based on the results of the systematic review of the best available evidence surrounding the risk and resilience factors identified in the public consultation period and the Guideline Development Group. The Guideline Development Group acknowledges the importance of culture to strength and resilience for Aboriginal and Torres Strait Islander people however the risk/resilience factors included were identified as part of a public consultation process and voting by the Guideline Development Group, in line with guideline processes and as such we are unable to add it at this point in the guideline development. No amendment has been made in response to this comment.
	Guideline	Future Research Priorities	65		Reference to the National Agreement on Closing the Gap and the four Priority Reforms should be referenced here:	Thank you for your comment. A reference to the National Agreement on Closing the Gap has been referenced in "Consideration of issues relevant to

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					 PR 1 = Formal partnerships and shared decision making PR 2 = Building the Community-Controlled sector PR 3 = Transforming Government Organisations and PR 4 = Shared access to data and information at a regional level. Aboriginal and Torres Strait Islander people must be involved in determining (and implementing and reporting on the findings of) future research priorities. 	Aboriginal and Torres Strait Island peoples" on pg. 19. Additional information: "These considerations will align with the National Agreement on closing the gap and the four priority reforms. Practitioners should also ensure collaboration with Aboriginal and Torres Strait Islander Health practitioners, health workers, and liaisons, as well as local/national Aboriginal Community Controlled Organisations (ACCHO's) to ensure a culturally safe approach to care [5]. Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6, 7]."
Organisation [10]	Guideline	Methods, Item 2,	28		 Change "This guideline was developed" instead of development – See Bold and Underlined 2. METHODS This guideline was <u>development</u> according to the Australian National Health and Medical Research Council (NHMRC) 	Amended

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					standards and procedures for rigorously developed external guidelines [5] and according to the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach [6].	
	Guideline	Data Extraction, Item 2.7	31		 Change to "data was extracted from included studies into 'Characteristics of included studies' tables – See Bold and Underlined. 2.7 Data extraction According to the selection criteria, data were extracted from included studies into 'Characteristics of included studies' tables (see Technical Report). Information was collected on study details, participants, results and risk of bias rating and GRADE certainty of evidence assessment rating. 	Amended
	Guideline	Data Synthesis, Item 2.8	32		Change to "Narrative synthesis was used as the data collected was not appropriate for meta-analysis" – data collected was not – instead of were – See Bold and Underlined 2.8 Data synthesis In order to summarise systematic review findings to inform evidence-based recommendations, data were presented in tables. Narrative synthesis was used as the	Amended

collected were n-analysis.not appropriate for Thank you for your comment. This section of the background has been amended in response to another
irment in an abbreviated term and later explained on page 39 – Swapsection of the background has been amended in response to another
nd. comment.
Processory impairment pared with children born at full-term, ren born VP have a higher rate of ness, deafness and cerebral palsy Precise definitions of the individual omes vary across studies and so too their reported prevalence. In general, ever, blindness and deafness occur ively infrequently (<5%), while CP (5- and cognitive impairment (defined as a than 2SD below age ctations/below the 2nd percentile; up 1%) are more common [21-25]. While proup-level prevalence of <u>NDI</u> may in relatively constant across hood, the severity of NDI changes for a third of children born VP from 2 to 8 is [26].

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					difficulties in important developmental domains for children born VP, including cognition, language/communication, motor skills, feeding, behaviour, and social skills. Research studies often combine blindness, deafness, cerebral palsy (CP) and cognitive impairment to form a composite outcome of neurosensory or neurodevelopmental disability or impairment (hereafter termed NDI).	
	Guideline	Quality of Life, Item 3.3	40		Remove the word VERY (See Bold and Underlined)Quality of LifeHealth-related quality of life refers to an individual's perception of their physical and mental health. In children, this is measured using standardised questionnaires with parents or caregivers as respondents. Health-related quality of life is on average lower for children born EP than those born at full-term, with some evidence that children born in more recent years may have poorer quality of life than those born in the 1990s [50, 51]. Very long-term follow-up also indicates that adults born VP/VLBW have reduced health- related quality of life, relative to their term-born peers [52]. However, resilience is also reported in the literature for both	Amended

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					young people born VP, particularly those without major disability [53], and their caregivers [7].	
	Guideline	Quality of Life, Item 3.3	40		Double check evidence – is that statement, correct? https://fn.bmj.com/content/107/4/408 Health-related quality of life is on average lower for children born EP than those born at full-term, with some evidence that children born in more recent years may have poorer quality of life than those born in the 1990s [50, 51]	Thank you for your comment. Parent report showed a decline in health- related quality of life ratings for EP children with increasing age. This was reported in the EPICure (50) as well as the VICs cohorts (51). No amendment has been made in response to this comment.
	Guideline	Follow-up Care after Very Preterm Birth, Item 3.4	41		Grammar changes -See Bold and Underlined3.4 Follow-up Care after Very Preterm BirthThe Current Landscape of Follow-up Care in AustraliaIn Australia, many infants born at (remove at) high-risk have access to preterm- specific follow-up care after discharge from hospital, but there remains substantial variability in the nature of this care for children born VP. All level III neonatal intensive care units (NICUs) in Australia provide follow-up for children born EP and/or ELBW at 2-3 years' corrected age,	Amended

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					and these (replace with this) data are (replace with is) collated by the Australian and New Zealand Neonatal Network [9].	
					A high proportion of eligible children attend <u>(add in a</u>) follow-up between 18 and 42 months' corrected age, however, around 15% do not receive (add in a) follow-up in the toddler period.	Thank you for your comment. Follow-up refers in this context to any appointment/review during this period. No amendment has been made in response to this comment.
					Follow-up <u>s</u> later into childhood <u>is (change</u> <u>to are)</u> essential to monitor the emergence of further skills and abilities but is not yet a widely available standard of care.	Thank you for your comment. Follow-up refers in this context to any appointment/review during this period. No amendment has been made in response to this comment.
	Guideline	Follow-up Care after Very Preterm Birth, Item 3.4	41		Grammer changes – See Bold and UnderlinedCaregivers' Values and Preferences Regarding Follow-up CareA narrative review of the literature indicated that there are many areas of priority (plural priorities) for families and health professionals with respect to outcomes of preterm birth. Although there is much research into the long-term	Thank you for your comment. No amendment has been made in response to this comment.

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					traditionally researchers and clinicians have selected outcomes to be studied, rather than <u>(missing a word here? Perhaps</u> <u>feedback or information from</u>) families who have experienced very preterm birth [62, 63].	
	Guideline	Follow-up Care after Very Preterm Birth, Item 3.5	43/44		Grammar changes – See Bold and Underlined.Supporting Children born Very Preterm to Transition Successfully to Formal SchoolingCommencing formal schooling is a key milestone in childhood, marking the end of the early childhood period. School readiness encompasses the child's readiness to participate in education, their family's readiness to support their educational needs, and their school's readiness to facilitate their learning. For children, school readiness refers to competence in five areas of development, including physical development, social- emotional maturity, language skills, cognitive skills, and their approaches to learning [67]. As a group, preschool-aged children born very preterm are two to five times more likely than full-term born children to have difficulties in each of the	Amended

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					five areas important for school readiness [68, 69]. Between 44-46% of children born VP present with vulnerabilities in two or more areas of school readiness, compared with 15-16% of children born full-term [68, 69]. Having two or more areas of vulnerability is predictive of later educational difficulties [68]. Even amongst children not already identified as having a physical or intellectual disability or other special need <u>(add an S after need)</u> , those born very preterm were around 1.5 times more likely than those born at term to be developmentally vulnerable in two or more domains important for school readiness [70]. This evidence emphasises the need for long-term multi-domain follow-up for children born very preterm beyond the infant and toddler years, and the intersection between health and early childhood education services in supporting children born very preterm to thrive.	
	Guideline	Follow-up Care after Very Preterm Birth, Item 4.4	47		Grammar changes -See Bold and UnderlinedSummary of narrative reviewDue to the minimal evidence on which to base recommendations, supporting evidence was considered from publications	Thank you for your comment. Amended to "In Australia, children born <28 weeks' gestation ("extremely preterm") or <100 g ("extremely low birthweight") may be offered review until age 2-3 years by follow-up clinics"

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					reporting from existing follow-up programs, organisational and collaborative position statements, and expert consensus recommendations regarding high-quality follow-up from national and international sources (<i>See Technical Report</i>). Clinical programs that follow-up children born very preterm or with other serious neonatal conditions exist around the world, with many offering follow-up care into the toddler years [9, 72-74]. However, there is considerable variability in the timing and type of follow-up programs reported [58, 75]. In Australia, children born <28 weeks' gestation ("extremely preterm") or <1000 g ("extremely low birthweight") may be offered <u>(add in a)</u> review <u>(add in at)</u> age 2-3 years by follow- up clinics associated with the 24 level III NICUs across the country. Follow up extends beyond the ages of 2-3 years in several states in Australia.	
	Guideline	Follow-up Care after Very Preterm Birth, Item 4.7	54		Grammar change – see Bold and Underlined Clinical considerations for implementation of the recommendations There are important considerations in planning for the adoption of this guideline.	Amended

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					In addition to guiding the process from research to recommendation, the GRADE Evidence to Decision Framework provided valuable context about the likely impact of this recommendation on clinical practice. As part of the GRADE Evidence to Decision Framework the GDG considered factors that <u>weight (should be weighed)</u> the risk versus benefit of recommendations.	
Organisation [11]	Guideline	Glossary	5-7		 Glossary items do not have references. Particularly it is suggested that the following definitions are reviewed: ADHD, ASD, DCD, cognition functions, IVH, NEC, Neonatal sepsis, Neurodevelopmental impairment, Retinopathy of prematurity, Periventricular leukomalacia. Glossary noted preterm as before 32/40 completed gestation, but later in the document, on page 21, talks about the correct definition of: This guideline is relevant to all children born very preterm at <32 weeks' gestation. 	Thank you for your comment. References have been added to the glossary. The following definitions were reviewed: ADHD, ASD, DCD, Cognitive functions, IVH, NEC, Neonatal sepsis, neurodevelopmental impairment, retinopathy of prematurity, periventricular leukomalacia. The glossary definition of very preterm has also been amended for consistency throughout the document.
	Guideline		14, 48	1	Great care should be taken when advising telehealth rather than face to face care. There are minor clinical findings which can have significant impact on outcome, which can be missed on video consultation, and certainly impossible on telephone	Thank you for your comment. Clinicians are encouraged to consider several factors when deciding to deliver face to face or telehealth care including family or clinician concerns. The guideline suggests face to face reviews for

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					consultations. Clinicians will not be able to assess eye contact and focus, hearing, muscle tone and to lesser extent muscle power, cardiac murmurs, accurate growth including weight, length and head circumference, skull abnormalities and torticollis, rickets, hernias and testicular issues, liver abnormalities, as well as more subtle clinical findings of neurocutaneous stigmata and so on. This can have a significant impact on the support provided and there is a risk of missing important findings. These can have significant impact on long term health outcomes	developmental assessment at 24 months corrected age and formal cognitive assessments at 4-5 years corrected age. We encourage services to be flexible in their approach to meet the needs, priorities and concerns of each individual child and caregivers, as mentioned in the clinical practice points. No amendment has been made in response to this comment.
	Guideline		17		Face to face assessment suggested for formal developmental assessment at 24 months corrected age and formal cognitive assessments at 4-5 years corrected age	Thank you for your comment. No action is suggested.
	Guideline	High risk groups	20-21, 22		Teenage mothers should be included as a high-risk group	Thank you for your comment. Teenage mothers have been added to the acknowledgement of groups that may be at higher risk of experiencing inequitable healthcare and outcomes.
	Guideline	Assessment tools	21		It is important to evaluate neurodevelopmental assessment tools, considering cost factors and workforce capability. There are paper based tools that parents complete vs face to face intensive developmental assessments like	The guideline does not provide an evaluation of specific tools that could be used for assessment. This is considered outside of the scope of the guideline. This can be found under 1.5 What the guideline does not address, page 17-18.

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					the Griffiths. The aim should be to use the best tool possible	No amendment has been made in response to this comment.
	Guideline	Relevant settings	23		 It is also important to note that most neurodevelopmental assessments have to be done by appropriately trained developmental paediatricians. The assessment of the neurodevelopmental assessment tools would be a very important process to assess what the workforce would look like, completing these assessments. The Griffiths developmental assessment is currently the preferred neurodevelopmental assessment tool in the Child development services in WA. Paediatricians working in the Child Development Services should be involved in the assessment process of best neurodevelopmental assessment tools. This has been acknowledged on page 51 to 52, and identified later in the document page 48: Clinicians should be appropriately trained/upskilled to assess the priority areas listed in these guidelines. 	The guideline does not provide an evaluation of specific tools that could be used for assessment. This is considered outside of the scope of the guideline. This can be found under 1.5 What the guideline does not address, page 17-18. No amendment has been made in response to this comment.
	Guideline		49		The Vaccination Schedule is only noted for discussion at 6 weeks post discharge and 8-9 months corrected age. It would be opportune to discuss the need for	Thank you for your comment. It is anticipated that discussions of supplemental immunisations for infants identified with any medical risk

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					supplementary immunisations for infants identified with any medical risk conditions at ages 18 months and 4-5 years. The identification of relevant infants should be supported in relevant ICT systems for recalls.	conditions would occur during general health reviews if medical risk conditions were identified. No amendment has been made in response to this comment.
Organisation [12]	Guideline	Chapter 1	47	4.5	The 'Evidence to recommendation statement' states that consensus-based recommendations are needed to "raise awareness" for structured, preterm specific follow-up care. The authors could consider noting who needs their awareness raised. For example, awareness could be raised among: - The community - Policy makers and funding bodies - Clinicians in the acute and community setting such as Doctors, Nurses, Midwives, Allied Health specialists Professionals involved in care and education of children such as teachers, early-learning educators, social workers, disability support workers.	Thank you for your comment. I have added additional text to this section. "amongst the community, policy makers and funding bodies, clinicians in the acute and community setting, such as doctors, nurses, midwives, allied health specialists, and professionals involved in the care and education of children, such as teachers, early- learning educators, social workers and disability support worker."
	Guideline	Chapter 1	48	4.6	Whilst the recommendation speaks to ensuring follow-up is flexible and individually tailored, it does not identify that cultural safety is an essential component to enable successful	Thank you for your comment. Additional information has been added to the Considerations of issues relevant

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					engagement and meeting the needs of First Nations and culturally diverse families. The authors could consider noting that supporting the growth of the Aboriginal health workforce, appropriate utilisation of Aboriginal health workers, cultural liaisons and interpreters, could enhance culturally safety.	to Aboriginal and Torres Strait Islander peoples on page 19. <i>"Important considerations for implementation of the guideline for</i> <i>Aboriginal and Torres Strait Islander</i> <i>people will be considered in the</i> <i>development of the Dissemination and</i> <i>Implementation Plan. These</i> <i>considerations will align with the</i> <i>National Agreement on closing the gap</i> <i>and the four priority reforms.</i> <i>Practitioners should also ensure</i> <i>collaboration with Aboriginal and Torres</i> <i>Strait Islander Health practitioners,</i> <i>health workers, and liaisons, as well as</i> <i>local/national Aboriginal Community</i> <i>Controlled organisations (ACCHO's) to</i> <i>ensure a culturally safe approach to</i> <i>care [5]. Culturally safe and appropriate</i> <i>care should be prioritised in the</i> <i>Aboriginal and Torres Strait Islander</i> <i>population, especially those with added</i> <i>complexities such as living in remote</i> <i>communities whose access to care is</i> <i>already reduced [6, 7]"</i>
	Guideline	Chapter 1	49	Follow-Up Schedule	It is noted that 'feeding' assessment ceases at 12 months (and is omitted from schedule at 8-9 months), and is replaced by a 'nutrition' assessment in the physical	The follow-up schedule recommended as part of this guideline is recommended as a minimum set of contacts and priorities and services and

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Submission		Document	Number	Number	 health/growth section. Advice and support regarding feeding and nutrition should continue to be provided at every visit, irrespective of height and BMI. It should also be noted that Mothers may cease or alter breastfeeding or formula feeding and children may encounter challenges, allergies and/or fussiness with the introduction of solid foods. Children are at high risk of iron deficiency, and this may be present even when a child has a normal BMI. Parents require ongoing support to provide healthy food choices for their children. 	 clinicians should offer more support as they consider appropriate. The guideline recommends a review of feeding at specific timepoints in association with development e.g. transition to solids. It is expected that concerns regarding feeding would be reviewed under nutrition review ongoing. It would be expected that clinicians would provide additional follow-up and/or referrals outside of the proposed schedule based on their clinical judgement such as in your example of children who encounter challenges when transitioning to solids. No amendment has been made in response to this comment.
	Guideline	Chapter 1	52	Commonly Used Measurement Options	In the Follow-Up Schedule it is noted that in the 'Wellbeing, Mental Health' schedule that 'parent-child attachment' should be assessed. However, in the commonly used measurement options there are no tools listed which identify ways that clinicians can assess attachment within the parent- child diad. Assessment of attachment styles is complex, with a national skills- shortage in this field, including presence of referral pathways for diads where insecure	The guideline does not provide an evaluation of specific tools that could be used for assessment. This is considered outside of the scope of the guideline. This can be found under 1.5 What the guideline does not address, page 17-18. No amendment has been made in response to this comment.

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					attachment style is suspected and/or identified. The authors of the CPG could consider identifying the lack of an appropriate 'measurement tool' for this particular assessment, and note the need for further investment into resources regarding assessment and intervention relating to infant attachment.	
	Guideline	Chapter 1	54		Typo. Two full stops in the summary section of 'What is the overall certainty of the evidence of effects'.	Thank you for the comment. This typo has been amended.
	Guideline	Chapter 2	58	Risk/Resilience Factors Association with Outcomes Summary	It is not noted whether identifying as a First Nations person is associated as a risk/resilience factor. Given that SES (lower), CALD and remoteness are identified as singular risk/resilience factors, consideration could be given as to whether being First Nations should be included as a risk/resilience factor. In many national strategies and CPG, First Nations people are not grouped together with all CALD populations. It is important to identify First Nations people independently and to have their data analysed as a stand-alone group.	Thank you for your comment. The guideline development team was limited in the data available for First Nations people. We acknowledge that at the time that the decision was made to capture data from the existing research First Nations was not considered as an independent group. We acknowledge that in the next iteration of the guideline First Nations should be considered as a stand alone group and the future research recommendations on page have been amended to reflect this:
						<i>"Future research about risk and resilience factors that assesses their suitability for health, community and disability care decision making would</i>

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						add value, including those specific to an Aboriginal and Torres Strait Islander peoples."
Organisation [14]	Guideline	Glossary	5	Autism Spectrum Disorders	This is not the accepted definition of ASD in Australia. Needs to accurately reflect DSM 5 TR definition or that used in the National Guideline ie: ASD is the collective term for a group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction, and by repetitive patterns of behaviour and restricted interests.	Thank you for the comment. This has been amended as per your feedback.
		Glossary	6	Neurodevelopmental impairment	This is not a condition outside of research and can be confused with the term neurodevelopmental disorder. Recommend clarifying this better in the glossary or better yet use neurosensory impairment with your description. If talking about general development, should all other developmental domains not be included? For many people outside the hospital sensory impairments are often referring to the sensory differences seen in ASD so need to review this terminology through the document	Neurodevelopmental impairment is a term used to describe sensory, motor and/or cognitive impairments. The terms does not refer to a cause and can be a result of multiple causes. We have modified the definition in the glossary: A condition whereby there is a composite of sensory (i.e. vision, hearing), communication, motor, and/or cognitive impairments, and be a result of different causes.
		Abbreviations	8	DCD	Either needs to be DCD=Developmental Coordination Disorder or DCDQ=	Thank you for your comment. The abbreviations have been amended to

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					Developmental Coordination Disorder Questionnaire	include DCD -Developmental Coordination Disorder.
	Consensus based recommendation Follow up Schedule	49 4.6 Consensus recommendation 1	 By specifying formal developmental assessment and formal cognitive assessment, you have excluded all second level screening tools which might actually be more-acore appropriate eg Ages and Stages Questionnaire. Consider using the terms developmental screening or cognitive screening instead or even review instead of screening. For consistency and clarity use the same terms 'screen for emotional-behavioural concerns' at both 24mo and 4-5y CA Needs more clarity about including clinical 	Thank you for your comment. The Guideline Development Group feels screening is not appropriate at this stage due to the risks of false positives and negatives in this high-risk group. No amendment has been made in response to this comment.		
					judgement in choice of tools	 Thank you for your comment. The tools included in Table 4 are both predictive and prognostic tools for services/clinicians to consider based on the needs of their follow-up reviews. The text above this table has been amended to further assist with clarification. Further evaluation of assessment tools was outside the scope of the guideline.
					What is meant by pre-academic skills: this has not been used or mentioned elsewhere	Thank you for your comment. Pre- academic skills refers to school

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		Clinical practice point	51	Table 4	CELF-5 cannot be used under 5. CELF-P3 commonly used in pre-prep children ASQ, m-CHAT, SACS, CBCL are screeners not assessment tools	readiness and can be found in the outcomes of interest on page 52. School readiness is further detailed in the background section under Supporting Children born Very Preterm to Transition Successfully to Formal Schooling on page 40-41. No amendment has been made in response to this comment. Thank you for your comment. The tools included in Table 4 (now Table 11) are both predictive and prognostic tools for services/clinicians to consider based on the needs of their follow-up reviews. The text above this table has been amended to further assist with clarification.
Individual [16]	Guideline	Executive summary	15		The two consensus based recommendations are difficult to differentiate. Reading them side by side I had to read them multiple times to find the difference, and even then it's unclear exactly what means. Consensus one is fleshed out adequately throughout. Consensus 2 feels like an afterthought, and after reading everything I still don't really know what you mean.	Thank you for your comment. The recommendations have been combined in the Summary of Recommendations Document however remain separated in the guideline as to reflect the outcomes of the two separate systematic reviews conducted.

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	Guideline	Intro	22	1.6-1.7	1.6 says recommendations not provided for Aboriginal and Torres Strait Islander children. 1.7 says recommendations consider Aboriginal and Torres Strait Islander children. Appears immediately contradictive.	Thank you for your comment. The guideline does not include separate recommendations for Aboriginal and Torres Strait Islander Children but does include special considerations for this group in the section titled "Considerations of issues relevant to children and families that may have additional or different needs". No amendment was made in response to this comment.
	Guideline	Recommendations	51	Table 4	All other assessments in bold have a corresponding 'X'' timepoint in bold except for the HINE. Is the recommendation from the GDG to do this at all four 'X" timepoints?	Thank you for your comment. The timepoint 6-12month CA has been bolded in response to your comment based on the clinical experience of members of our Guideline Development Group.
Organisation [17]	Guideline	Consensus-based Recommendation: Follow-Up Schedule	49/50		• The document really doesn't provide what is 'follow-up' care – with each jurisdiction having its own Key Ages and Stage visits, this could be useful if there is an age point that an individual State/Territory doesn't offer (Vic and NT do) i.e. does everyone have occasions of service at these age points already?	Thank you for your comment. I draw your attention to 3.4 Follow-up care after very preterm birth. The availability of follow-up for children born very preterm is highly variable across the country. It is likely that there are many places across the countries providing excellent follow-up care services through existing services for the very preterm population. This guideline aims to improve the consistency of that care.

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					• What is the time allocation for each of these 'visits? Funding???	 Thank you for your comment. An economic evaluation was not part of this guideline and resource use in forming recommendations was not considered. A dissemination and implementation plan will be developed alongside the next version of the guideline. Your comment has been noted for the development of this plan.
Organisation [18]	Guideline	Chapter 4	48	1	In providing pre-term specific follow-up care, service providers should also consider the following practice points: culturally safe services and service providers, choice of service provider, the impact of intergenerational trauma and racism on engagement with follow-up care for First Nations caregivers, caregivers who live in rural and remote areas (where accessibility to services and/or transport is limited), the level of caregiver education.	Thank you for your comment. Additional information has been added to the Consideration of issues relevant to Aboriginal and Torres Strait Islander Peoples on page 19. "Important considerations for implementation of the guideline for Aboriginal and Torres Strait Islander people will be considered in the development of the Dissemination and Implementation Plan. These considerations will align with the National Agreement on closing the gap and the four priority reforms. Practitioners should also ensure collaboration with Aboriginal and Torres Strait Islander Health practitioners, health workers, and liaisons, as well as local/national Aboriginal Community

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						Controlled organisations (ACCHO's) to ensure a culturally safe approach to care [5]. Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6, 7]."
	Guideline	Document			The draft guidelines make no reference to paediatric palliative care in regards to babies born prematurely with a life limiting illness. We also note that there doesn't appear to be a representation from paediatric palliative care in regards to consultation. Would it be appropriate to either add references throughout the guidelines to paediatric palliative care, or in the Section that refers to what the guidance material does not cover include that it does not specially reference paediatric palliative care available for those preterm babies born with life limiting illness, and that information on this can be found in the Paediatric Palliative Care National Action Plan. The Paediatric Palliative Care National Action Plan - Paediatric Palliative Care	Thank you for this comment. We have added paediatric palliative care to the section on what the guideline does not cover and made reference to the Paediatric Palliative Care National Action Plan on page 18.

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	Guideline	Document			The term corrected age needs to be defined as this term may not be understood by parents and others who are not health professionals	Thank you. Corrected age has been added to the glossary.
Organisation [20]	Guideline	PLS	14	Consensus based recommendation 2	It is acknowledged the GDG is aiming to ensure access and avoid the use of cut- points for weight/gestation/other risk factors or even positive early clinical progress to determine inclusion or exclusion criteria. It is agreed that at point of discharge from NNU all children have unquantified risk and all require follow up. However, the wording of recommendation 2 could be misinterpreted and is a little confusing. Consider: Structured, preterm-specific follow-up care should be offered to all children born very preterm and their caregivers regardless of perceived risk and/or resilience factors.	Thank you for your comment. Consensus based recommendation 2 has been altered to include 'all' children throughout the document for clarity however the recommendation is based on the presence of risk and/or resilience factors that were the subject of systematic review 2.
	Guideline	PLS	14	Descriptor of recommendation 2.	Consider addition: Clinicians should consider changing the modality of assessmentfrequency of appointments, type of assessments and supports offered based on the emerging needs of each child and their family.	Thank you for your comment. Amended as suggested.
	Guideline	Executive summary	15	Clinical practice points	We endorse CPP 10 – "Services should be flexible in their approach to providing	Thank you for your comment. Amended as suggested.

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					follow-up" but we suggest a minor change in wording to highlight the role of early clinical assessment in determining need for additional appointment scheduling. I.e. "based on family's preferences, clinical needs, early assessment findings and other relevant factors."	
	Guideline	Introduction	19	1.	Consider a word change: Organisations responsible for funding decisions can use this guideline to develop a greater understanding of the benefits (not challenges) of structured follow up and make a difference for children born very preterm and their families.	Thank you for your comment. Amended as suggested.
	Guideline	Context	19	1.1	Consider removing or rewording "further negatively affecting their outcomes" given there is a lack of evidence of the quantifiable benefit of follow up programs for preterm infants and caregiver mental health.	Thank you for your comment. We have added 'potentially' as you are correct in pointing out that there is a lack of evidence of the quantifiable benefit of follow-up programs however theoretically it is possible that this will further negatively affect the children's outcomes.
	Guideline	Purpose of the Guideline	20	1.2	We agree with the guiding principles decided by the GDG and we are especially pleased to see acknowledgement that "different level of surveillance may be appropriate for different children." This promotes options for cost effective prioritised services and discharge from	Thank you for your comment. No amendment is required in response to this comment.

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					acute/specialist services and facilities to universal care in the community for children identified in early assessment as having lower risk for adverse outcome. We also endorse the related statement p. 36 "it is important to acknowledge that many children born VP (now the majority) have age-appropriate long-term development and many caregivers experience comparable quality of life to caregivers of full term children in the longer term".	
	Guideline	Clinical Question	29	2.3, paragraph 2, 2nd sentence	Consider revising this rather long and confusing sentence.	Thank you for your comment. The sentence has been revised.
	Guideline	3.3 NSI	38	Reference 26	Interpretation appears inaccurate and is somewhat misleading. From 2-8 years, 20% of children improved, 17% deteriorated and 63% remained in the same category (normal, mild, moderate to severe delay). There were no specific findings about "group level", rather individual trajectories.	Thank you for your comment. Van Beek 2021 (previously reference 26) notes that individual longitudinal trajectories over time were studied with an observed individual variation over time in NDI status in 37% of children (pg.5). The sentence on page 35 has been amended in response to your comment to read:
						"While the group-level (normal, mild, moderate to severe delay) prevalence of neurodevelopmental impairment (NDI) may remain relatively constant across childhood, the individual variation of

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						NDI status changes for over a third of children born VP from 2 to 8 years [30]".
	Guideline	3.3 Developmental	39	Reference 39	Please revise: Language scores were 1SD below mean compared to term born controls, not age-expected levels.	Thank you for your comment. Text has been amended on page 36 to read: "scores 1SD below mean of term born controls)"
	Guideline	Table 4	51	CPP measurement options	 Overall recommendation - consider removing Table 4 as out of scope. Specific feedback: Multiple domains - Bayley 4 age D/C to 3 months should not be included. No published information of version 4 is available in systematic reviews and based on previous systematic review (Caesar et al 2021) the Bayley assessment (previous versions) used up to 6 months CA had no predictive utility for longer term outcome. Motor - HINE - Can be used from 3 months but recommendation for improved sensitivity and specificity for cognitive outcomes after 6 months. (Romeo et al. 2022) NSMDA can be used from 1 month 	Thank you for your comment. Table 11 (previously Table 4) was included as generalised start point for clinicians to consider tools relevant to their needs and the needs of the families they are working with. The description of the table has been amended for further clarification. <i>"The Guideline Development Group</i> <i>(GDG) discussed the need for guidance</i> on predictive and prognostic tools to assist with the delivery of structured preterm specific follow-up for children born very preterm. The evidence investigating specific tools was outside the scope of this guideline, therefore the GDG has developed the below clinical practice points based on the GDG's experience only. This table is not intended to be comprehensive or the only tools that could be used to guide follow-up of children born very preterm.

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						It is intended as a starting point from which clinicians/services should consider tools to achieve the same goals based on the experience and expertise of available staff."
						Additionally, the tools mentioned have been reviewed and the below changes made:
						Bayley 4 and HINE are not suggested between D/C to 3mo CA.
						A footnote has been added for the NSMDA noted that it can be used from 1 month CA.

4.3 Feedback on Additional Evidence

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		Number			team
Organisation	Feedback on Additional		Woodward, B., Papile, LA., Lowe, J. et al. Use of the Ages and Stages Questionnaire		Thank you for your comment. The evaluation of individual
[6]	Evidence:		and Bayley Scales of Infant Development-II in neurodevelopmental follow-up of		tools was outside the scope of the guideline.
	Clinical Practice Point: Commonly used		extremely low birth weight infants. J Perinatol 31, 641–646 (2011). https://doi.org/10.1038/jp.2011.1		the guideline.
	measurement				

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	options, Table 4, pg. 51		Yu LM, Hey E, Doyle LW, Farrell B, Spark P, Altman DG, Duley L, Magpie Trial Follow-Up Study Collaborative Group. Evaluation of the Ages and Stages Questionnaires in identifying children with neurosensory disability in the Magpie Trial follow-up study. Acta paediatrica. 2007 Dec;96(12):1803-8. GDG may like to consider this study in evaluation of ASQ versus Bayleys scales.		
Organisation [7]	Introduction	1,7	National Agreement on Closing the Gap and Four Priority Reforms <u>https://www.closingthegap.gov.au/national-agreement</u>	 All levels of government across Australia have committed to the National Agreement on Closing the Gap and four priority reforms: 1) Formal partnerships and shared decision making 2) Building the Community- Controlled sector 3) Transforming Government Organisations and 4) Shared access to data and information at a regional level. 	Thank you for your comment. The National Agreement on Closing the Gap and Four Priority Reforms has been referenced in the background under consideration of issues relevant to Aboriginal and Torres Strait Islander peoples.
	Introduction	1.6, 1.7	Gao et al. (2023). Birthing on country service compared to standard care for First	This article highlights the potential role of the ACCHO sector in	Thank you for your comment. This reference has been added

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			Nations Australians: a cost-effectiveness analysis from a health perspective. <i>The</i> <i>Lancet Regional Health – Western Pacific,</i> <i>34</i> , 100722. doi: 10. 1016/j.lanwpc.2023. 100722	improving Aboriginal and Torres Strait Islander peoples, which could be considered in the narrative review.	to the 'Follow-up Care after Very Preterm Birth' section. "Aboriginal and Torres Strait Islander families should be linked in with services to support access to ongoing care, through local Aboriginal Cooperation's, Aboriginal Community Controlled Health Organisations, and hospital supports."
	Introduction	1.6, 1.7	Thackrah RD, Wood J, Thompson SC. (2020). Cultural respect in midwifery service provision for Aboriginal women: longitudinal follow-up reveals the enduring legacy of targeted program initiatives. <i>International Journal for Equity in Health</i> , 19:1-1. doi: 10.1186/s12939-020-01325-x	This study outlines the importance of cultural safety and respect in midwifery service provision for Aboriginal and Torres Strait Islander women. Cultural safety needs a stronger emphasis and focus in these guidelines.	Thank you for your comment. This reference has been added to the 'Follow-up Care after Very Preterm Birth' section. "Aboriginal and Torres Strait Islander families should be linked in with services to support access to ongoing care, through local Aboriginal Cooperation's, Aboriginal Community Controlled Health Organisations, and hospital
	Background	3.1, 3.2	Australian Institute of Health and Welfare (2021). Pregnancy and birth outcomes for Aboriginal and Torres Strait Islander women: 2016-2018. <i>AIHW</i> .	There are compelling data relating to the inequitable burden of premature births experienced by Aboriginal and Torres Strait Islander	supports." Thank you for your comment. Unfortunately, this document does not include data specifically on children born before 32 weeks completed

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				communities. These should be acknowledged.	gestation. No amendment was made in response to this comment.
	Background	3.3	Australian Institute of Aboriginal and Torres Strait Islander Studies (2023). The Stolen Generations. [Internet]. AIATSIS. Available from: <u>The Stolen Generations AIATSIS</u>	The persisting impacts of the Stolen Generations and other issues affecting Aboriginal and Torres Strait Islander peoples contribute to intergeneration trauma and gaps in health outcomes, and should be referenced.	Thank you for your comment. The Guideline Development Group acknowledges the persisting impacts of the Stolen Generations and their contribution to intergenerational trauma. The guideline stresses the challenges of the experience of VP birth on all caregivers in section the background. No amendment was made in response to this comment.
	Chapter 1	1	Bailey et al. (2023). Early mortality among aboriginal and non-aboriginal women who had a preterm birth in Western Australia: A population-based cohort study. <i>Paediatric</i> <i>and Perinatal Epidemiology, 37</i> (1), 31-44.	The findings of this study suggest that mothers of preterm babies are at risk of early mortality, particularly in Aboriginal and Torres Strait Islander mothers, and are relevant to the section detailing <i>Physical Health</i> of preterm children.	Chapter 1 refers to the results of the systematic review of structured follow-up programs. The domains identified were the result of public consultation and subsequent Guideline Development Group voting as per the guideline processes and cannot be added at this stage of the guideline. No amendment has been made in response to this comment.

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	Chapter 1	1	Dossetor et al. (2019). Review of Aboriginal child health services in remote Western Australia identifies challenges and informs solutions. <i>BMC Health Services Research</i> , <i>19</i> (758).	Rural and remote child health services are fragmented and inadequate, while mothers living in these regions are more likely to give birth to a preterm baby. Pre-term specific community-controlled antenatal and follow-up paediatric services in these regions should be prioritised from an equity perspective.	Thank you for your comment. This article has been referred to in the background under consideration of issues relevant to Aboriginal and Torres Strait Islander peoples. "Culturally safe and appropriate care should be prioritised in the Aboriginal and Torres Strait Islander population, especially those with added complexities such as living in remote communities whose access to care is already reduced [6,7]"
	Chapter 2	5.1 - 5.5	 Wouldes, T. A. (2022). Fostering resilience to very preterm birth through the caregiving environment. <i>JAMA Network</i> <i>Open</i>, <i>5</i>(10), e2238095-e2238095. doi:10.1001/jamanetworkopen.2022.38095 Westrupp, E. M., D'Esposito, F., Freemantle, J., Mensah, F. K., & Nicholson, J. M. (2019). Health outcomes for Australian Aboriginal and Torres Strait Islander children born preterm, low birthweight or small for gestational age: A nationwide cohort study. <i>PloS one</i>, <i>14</i>(2), e0212130. doi: <u>10.1371/journal.pone.0212130</u> 	The document currently promotes a deficit approach (e.g. section 5.3) to risk and resilience factors. There is plentiful evidence supporting the importance of health promotion, building resilience and adopting a strengths-based approach in order to improve health outcomes for Aboriginal and Torres Strait Islander children born preterm. As per the comments above, a domain that includes a strengths-based focus on culture and community must be considered.	Thank you for your comment. The Guideline Development Group acknowledges the importance of culture to strength and resilience for Aboriginal and Torres Strait Islander people however the risk/resilience factors included were identified as part of a public consultation process and voting by the Guideline Development Group, in line with guideline processes and as such we are unable to add it

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505111551011	Document	Number	Australian Institute of Health and Welfare		at this point in the guideline
			(2023). Aboriginal and Torres Strait Islander		development. No amendment
			Health Performance Framework – Summary		has been made in response to
			Report July 2023: 2.21 Health behaviours		this comment.
			during pregnancy. [Internet]. AIHW.		
			Available from: 2.21 Health behaviours		
			during pregnancy - AIHW Indigenous HPF		
			Kildea, S et al. (2021). Effect of a Birthing on		
			Country service redesign on maternal and		
			neonatal health outcomes for First Nations		
			Australians: a prospective, non-randomised,		
			interventional trial. The Lancet Global		
			<i>Health, 9</i> (5), e651-e659. doi: 10.1016/		
			S2214-109X(21)00061-9		
			National Indigenous Australians Agency		
			(2021). National Aboriginal and Torres Strait		
			Islander Early Childhood Strategy.		
			[Internet]. NIAA. Available from: National		
			Aboriginal and Torres Strait Islander Early		
			Childhood Strategy National Indigenous		
			Australians Agency (niaa.gov.au)		
Organisation	Feedback on		Mental Health Care in the Perinatal Period		Thank you for your comment.
	Additional		cope.org.au Australian Clinical Practice		This study was not identified as
[10]	Evidence		Guideline 2023 REVISION		meeting the inclusion criteria
	Pg. 61, 5.3		https://www.cope.org.au/health-		for this review and further
	Summary of		professionals/health-professionals-		information was not included
	evidence		<u>3/review-of-new-perinatal-mental-health-</u>		due to the breadth of the systematic review. We
	review		guidelines/		acknowledge the importance
					acknowledge the importance

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			Parental mental health - No studies reporting associations of parental mental health with any subsequent outcomes of interest were identified as meeting inclusion criteria for this review		of parental mental health and it was considered in the development of the follow-up schedule, in which parental mental health is included in every timepoint in the scope of family wellbeing, mental health.
Organisation [18]				In terms of content there is no mention of context of why children may be born very preterm and how that may impact care of these children or their carers going forward ie the risk factors for preterm birth such as previous preterm birth, multiple gestations, various medical conditions and exposure to alcohol, other drugs, tobacco to name a few. There needs to be consideration of the ongoing impact of these factors eg drug dependence of infant, FASD which	Thank you for your comment. The guideline focuses on the follow-up of children born very preterm and their caregivers and not the risk or reasons for very preterm birth as this could be a stand-alone guideline. No amendment has been made in response to this comment.
				is very underdiagnosed. The document only refers to cerebal palsy in the follow-up schedule. There is opportunity for prevention here.	

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	4. Chapter 1: Structured Follow-up		Consensus-based Recommendation: Follow- up Schedule	One area with research found that structured follow-up did not affect the frequency of neurodevelopmental delay/impairment or cerebral palsy but it did lead to earlier diagnosis. However, it is unknown if this makes any difference, and the guidelines opt for a complex matrix of structured follow-up regardless, based on expert consensus. It would be useful to have some statistics to indicate how many children born very preterm will experience long term health and developmental difficulties or how much more likely they are to experience specific problems. This is done well in some areas (eg. in the section 'Supporting Children born Very Preterm to Transition Successfully to Formal Schooling') but is lacking in many other sections. It is useful to have specific information about increased risk and incidence as this provides context and reinforces the need for taking action.	Thank you for your comment. You are correct, that the evidence available on structured follow-up is limited to one study. The follow-up recommendation schedule has been developed based on consensus clinical experience of the guideline working group. The available evidence about short and long term health impacts of very preterm birth can be seen in the section The Impacts of Very Preterm Birth on Child Growth, Health and Development and Parent Wellbeing on pages 34-37. This section includes statistics of the likelihood to experience many of the specific outcomes of interest of the guideline. No amendment was made in response to this comment.

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				It would also be useful to provide some statistics around the increased likelihood of parents/caregivers experiencing poor mental health associated with having a child born very preterm as poor mental health amongst new parents is common.	Thank you for your comment. Please see the background section entitled "Impact on Parental Wellbeing" on page 37 and associated references for this information. No amendment was made in response to this comment.
				Having a history of preterm birth is a risk factor for having a subsequent preterm birth, it would be good if the "Wellbeing, Mental health" follow-up with the family could include some guidance and support for subsequent pregnancies - perhaps a recommendation for preterm birth prevention antenatal care.	Thank you for your comment. Information for subsequent births could be included in the resources/information needs included at every time based on the needs of the individual family. Clinicians should be utilising clinical judgement to discuss additional information needs with families.
	P15	Consensus-based Recommendation 1: Follow-up Schedule Recommendations	 Haslam D, Mathews B, Pacella R, Scott JG, Finkelhor D, Higgins DJ, Meinck F, Erskine HE, Thomas HJ, Lawrence D, Malacova E. (2023). The prevalence and impact of child maltreatment in Australia: Findings from the Australian Child Maltreatment Study: Brief Report. Australian Child Maltreatment Study, Queensland University of 	This report is relevant as it has found that family adversity increases the risk of multi-type maltreatment and family domestic violence.	Thank you for your comment. This report does not have specific information for children born very preterm. No amendment was made in response to this comment.

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Submission	Document	Number			team
			Technology. DOI: http://doi.org/10.5204/rep.eprints.239397 p22, 23,		