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

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Publication Approval

Australian Government
National Health and Medical Research Council

The guideline recommendations on pages 11 - 95 of this document were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 18 April 2024 under section 14A of the *National Health and Medical Research Council Act 1992*. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of five years.

NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting.

This publication reflects the views of the authors and not necessarily the views of the Australian Government.

In the spirit of reconciliation, the Centre of Research Excellence (CRE) in Newborn Medicine acknowledges the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginals and Torres Strait Islander peoples.

This guideline was produced by the CRE in Newborn Medicine in collaboration with the following organisations:

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Foreword

I would like to acknowledge the Traditional Custodians of the lands on which this guideline was developed. I pay my respects to their Elders, past, present and emerging.

Advances in maternal and neonatal care have seen increased survival of babies who are born very preterm, two to four months prior to their due date of birth. Many go on to lead healthy and productive lives. However, research also tells us that a greater proportion of babies born very preterm face challenges in health and many aspects of development compared with their peers who are born full-term. Although significant resources are allocated to advancing care after birth, i.e. in the neonatal intensive and special care nurseries, there is a disparity of attention and resource allocation to care after discharge from hospital. The follow-up care of very preterm babies lacks uniformity, which results in inequity of access and provision of post discharge care to over 3000 babies born very preterm (i.e. less than 32 weeks' gestation) per year in Australia. Families highlight post discharge follow-up care as a priority. Currently there is lack of systematic follow-up, lack of awareness of the challenges to health and development faced by very preterm children, and where to seek assistance for children and their families.

The Centre of Research Excellence (CRE) in Newborn Medicine is an initiative funded by the Australian National Health and Medical Research Council. One of the CRE's major translational initiatives was the development of this evidence-based guideline, which is a culmination of 18 months of dedication by many around the country. I would like to thank the following people:

To Professors Katrina Williams and Angela Morgan, Chairs of the Guideline Development Group (GDG), we are indebted to your dedication in guiding the GDG through the process. My fellow Steering Group members, Professors Peter Anderson and Rod Hunt, who contributed their wise views and thoughts. This work would not have been possible without the dedication of our Senior Project Officers, Drs Alice Burnett and Jamie Owen, who have led the work and taken it to fruition. A special thanks to the other members of the project team, Drs Abdulbasit Seid, Joy Olsen, and Samuel Axford. I am indebted to the unwavering commitment of the Development Group members (listed pages 20-23), a dedicated multidisciplinary group from across Australia (and 1 New Zealander) who have enriched the guideline with their broad insights which hopefully will ensure that the recommendations are relevant to the wider Australian context. Huge thanks to Professor Philippa Middleton and Dr Emily Sheppard from SAHMRI, for their generosity in advice regarding methodological aspects of the guideline development.

I hope that this guideline provides a framework for best evidence-based practice and will form an advocacy document for individual jurisdictions and families to advocate for best care. This guideline takes recommendations to school entry. It is out hope that a further initiative will take recommendations through school age, adolescence and adulthood.

To all the babies, children, adolescents, and adults who were born very preterm, and their families, I hope that this guideline will help pave the way for equity in care, to ultimately assist all of you to reach your full potential.

Professor Jeanie Cheong

Neonatologist, Royal Women's Hospital, Melbourne
Principal Research Fellow, Murdoch Children's Research Institute
Honorary Professorial Fellow, University of Melbourne

From The Chairs

We acknowledge the Traditional Custodians of the lands for which this guideline is developed, and pay our respects to all Elders, past, present and emerging. We also acknowledge the need to live in an undivided Australia, where all people are equal and have access to all they need to thrive.

We hope the language we have used throughout does not offend. Our identification of any specific groups within Australia is only intended to ensure there is awareness of a need for special considerations in care, which we hope will be to the advantage of individuals.

This is the first Australian Guideline for Growth, Health and Developmental Follow-up for Children Born Very Preterm. The Guideline provides consensus-based recommendations for follow-up for children who have been born very preterm and their families and carers, to guide decision making by health practitioners, educators, service providers, policy makers, researchers and communities. The Guideline was developed in accordance with NHMRC standards for clinical practice guidelines.

The Guideline Development Group (GDG) comprised a broad range of people with experience of very preterm birth, including those with a child born preterm, community members, professional groups, Aboriginal and Torres Strait Islander peoples, and health professionals. All GDG members had no identified or declared conflicts of interest.

Development of this guideline was funded by a Centre of Research Excellence grant from the NHMRC, with members of the steering group also investigators on that grant. Funding was used to employ Drs Alice Burnett and Jamie Owen to organise meetings, lead the systematic review process that has underpinned the recommendations included in this guideline, and write the first draft of the guideline. Drs Abdulbasit Seid, Joy Olsen and Samuel Axford were also employed to assist Drs Burnett and Owen with the systematic reviews.

Although much research has been completed about outcomes of children born very preterm, there was little evidence identified that directly informed the recommendations made. Rather the GDG brought a broad range of expertise to consider follow-up assessment recommendations that could support children and families and improve their outcomes.

We are indebted to the funders, to the NHMRC for providing a rigorous guideline development framework, to those organisations who have provided representatives or endorsement, to methodology experts Professor Philippa Middleton and Dr Emily Shepherd who donated their time, and to all the supporting staff listed above. We also gratefully acknowledge the extensive input from members of the GDG who donated their time, and to all those who provided feedback, support and advice.

This guideline has been developed in part during the course of the COVID-19 pandemic and indicates the commitment of the GDG members to continue despite the pressures that the pandemic brought.

It is our hope that this guideline 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 that enable the update in five years' time to include more evidence-based recommendations.

Professor Katrina Williams and Professor Angela Morgan

Plain Language Summary

Children born very preterm (<32 weeks) require intensive medical care to survive. Treatment for these children has improved over time and now the majority survive and, following a lengthy hospital stay, go home with their caregivers. Due to their early birth these children face increased risk of growth, health and developmental problems compared with children born full-term. Some difficulties present early in life and others later in the preschool years. Very preterm birth is distressing for caregivers and families as it is not what they anticipated, and that, along with additional carer burden, can have consequences for family wellbeing, mental health and quality of life.

Specific follow-up services for children born very preterm vary considerably across Australia. Many children may miss out on assessments important for identifying growth, health and developmental difficulties and therefore miss the opportunity for timely referrals for support, interventions and services for children and families.

This guideline makes recommendations for a structured, preterm specific post-discharge follow-up.

Consensus Based Recommendation 1:

Structured, preterm-specific post-discharge follow-up care should be offered to children born very preterm and their caregivers.

This guideline recommends structured, preterm-specific follow-up care be offered to all children born very preterm and their families. The follow-up schedule recommended offers a minimum set of contacts and priorities. This is needed because these children often experience growth, health and developmental difficulties that may be missed without appropriate follow-up services.

Consensus Based Recommendation 2:

Structured, preterm-specific follow-up care should be offered to all children born very preterm and their caregivers regardless of presence of risk and/or resilience factors.

Clinicians should consider changing the modality of assessment (i.e., in person versus telehealth), frequency of appointments and type of assessments and supports offered based on the emerging needs of each child and their family.

Executive Summary

Consensus-based Recommendation 1

Structured, preterm-specific post-discharge follow-up care should be offered to children born very preterm and their caregivers.

Consensus-based Recommendation 2

Structured, preterm-specific follow-up care should be offered to all children born very preterm and their caregivers regardless of presence of risk and/or resilience factors.

Clinical Practice Points

*In providing structured, **preterm-specific** follow-up care, service providers should consider the following practice points:*

1. This proposal offers a *minimum* set of contacts and priorities; services and clinicians should offer more support as they consider appropriate.
2. Follow-up should be provided in a flexible way to meet the needs, priorities and concerns of each individual child and caregivers.
3. Children with very complex conditions/specific needs may need additional specialised follow-up, e.g. retinopathy of prematurity monitoring, post-surgical follow-up.
4. Corrected age should be used when considering a child's growth, health, and development.
5. Involve key caregivers outside the family, such as early childhood professionals, to ensure a holistic view of children's wellbeing/functioning.
6. Children born very preterm, and their caregivers should have post discharge follow-up care planning initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible).
7. 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.
8. Clinicians should be appropriately trained/upskilled to assess the priority areas listed in these guidelines.
9. Establishing strong professional links with larger teams of expertise may help facilitate training and maintenance of professional development.
10. 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 a hybrid (e.g., telehealth contacts facilitated with a local healthcare professional) based on families' preferences, clinical needs, and any other relevant factors.

Consensus-based Recommendation 1: Follow-up Schedule Recommendations

Table 1 - Follow-up Schedule

Priorities	Shortly post-discharge (7-10 days)	6w post-discharge	3-4mo CA	6mo CA [ab]	8-9mo CA	12mo CA [c]	18mo CA [e]	24mo CA	2.5y CA [a]	4-5y CA [f]
Physical Health										
General health (incl. respiratory)	+	+ Vaccination Schedule [h]	+		+ Vaccination Schedule [h]	+	+	+		+ Cardiovascular (BP) Respiratory (asthma)
Growth	+	+	+		+ Height/BMI)/ Nutrition (incl. Feeding)	+ (Height/BMI)/ Nutrition	+ (Height/BMI)/ Nutrition	+ (Height/BMI)/ Nutrition		+ (Height/BMI)/ Nutrition
Sensory		+ Vision Hearing	+		+	+ Vision Hearing	+	+		+ Vision, Hearing
Developmental										
Feeding	+ Lactation support	+	+ Plan for starting solids			+				
Sleep	+	+	+		+	+				
Behaviour, Developmental progress, and support	+	+	+ Early detection of infants at high-risk of CP [c].		+ (language/ communication/ motor)	+ (language/ communication/ motor)	+ (language/ communication/ motor)	+ Formal developmental assessment [d] (cognition/language/ communication, motor), screen for emotional-behavioural concerns		+ Formal cognitive assessment [d] Pre-academic skills, Behaviour, Language/communication, Motor skills
Quality of Life										
For child and family						+				+
Family										
Wellbeing, Mental health [g],	+	+	+		+	+	+	+		+

Resources/ Information needs[i]	+ incl. milestones for CA	+	+		+	+	+	+		+

Abbreviations: mo: months, y: years, CA: corrected age, BMI: body mass index, BP: blood pressure

[a] Review if parental concerns or clinical need

[b] Telehealth check-in may be advised

[c] Expertise in early detection of CP. Novak et al. 2017 https://jamanetwork.com/journals/jamapediatrics/article-abstract/2636588

[d] Face to face assessment suggested for formal developmental assessment at 24 months corrected age and formal cognitive assessments at 4-5 years corrected age.

[e] Telehealth check in with face to face appointments if indicated

[f] Timing of contact to consider child's likely commencement of formal schooling.

[g] Including parent-child attachment

[h] Vaccinations administered via chronological age

[i] Consider socio-economic background assessment of family when considering information needs.

Introduction: Context, Scope, and Purpose of this Guideline

This Australian clinical guideline on growth, health and developmental follow-up for children born very preterm addresses the priorities of health professionals and people with lived experience of very preterm birth. The guideline was developed by systematically reviewing the available evidence which was presented to multidisciplinary clinical experts and consumers to develop recommendations and practice points relevant to clinicians, consumers and policy makers, for the Australian context.

The guideline promotes a structured, post-discharge growth, health and developmental follow-up schedule for children born very preterm.

Professionals, caregivers and other supporting services can use this guideline to advocate for and facilitate structured, post discharge follow-up for children born very preterm and their families. Health service providers and policy makers can use this guideline to guide local services and policy development. Organisations responsible for funding decisions can use this guideline to develop a greater understanding of the benefits of structured follow-up and that, with funding, appropriate follow-up can make a difference for children born very preterm and their families.

Context and background

Approximately 1.1% of babies born alive in Australia each year (i.e. ~3,300) are very preterm or before 32 completed weeks of gestation [1]. It is estimated that 55-60% (~1,800) of those will experience difficulties in their development [2, 3]. Children born very preterm have increased risk of growth, health and developmental difficulties and experiencing very preterm birth can also adversely affect the mental health and wellbeing of parents and caregivers (from here referred to as caregivers). It is critically important that difficulties are identified early, so that children can receive appropriate early intervention to optimise their growth, health and developmental outcomes and families can be supported. Currently, there are no Australia-wide guidelines for long-term follow-up for children born very preterm and practice varies widely. In addition, there is currently no national guideline about supporting caregivers after very preterm birth. This means that some children born very preterm, and caregivers of these children, will not have their needs recognised in a timely manner, potentially further negatively affecting their outcomes.

Purpose of the guideline

The overarching goal of this guideline is to help strengthen families who have experienced very preterm birth through promoting optimal growth, health and developmental outcomes for children, and the mental health and wellbeing of their caregivers across the infant and early childhood period. To achieve these goals, this guideline is intended to provide evidence-based guidance prior to the child commencing full-time formal schooling to ensure that problems are identified early and intervention offered in a timely manner. The guideline has been developed to be used by caregivers, Australian health providers who provide follow-up for infants and children born very preterm, service providers and policy makers. For the purposes of this guideline, we define “follow-up care” as healthcare provided after discharge from initial hospital stay that includes; monitoring of growth, health and

development, providing appropriate management within the scope of the service or health professional, and referring on for additional support, intervention, or investigation as needed. Numerous health professionals working in various settings may be involved in providing follow-up care to children born very preterm and their caregivers. Follow-up may be provided face-to-face or via online or phone services, as suitable to the follow-up needed and preferences of each family.

This guideline includes recommendations for age of follow-up, the domains of growth, health and development that need specific attention, and the factors that may influence the risk of growth, health and developmental difficulties after very preterm birth. As well as child growth, health and development, we explicitly include caregiver mental health and wellbeing as important health outcomes after very preterm birth. The guideline will also provide practice points relevant to assessment elements and approaches. This will increase consistency and equity of follow-up care, improve early identification of growth, health and developmental difficulties, and ultimately improve outcomes for children born very preterm and their caregivers.

The guideline was developed based on the following guiding principles, as decided by the Guideline Development Group:

- Follow-up care should be family centred, flexible, resource efficient, and consistent.
- Follow-up should be equitable, culturally safe, and appropriate to each individual child and family's needs, preferences, and values.
- Many factors will influence how follow-up services operate and continuity of care and coordination between health professionals and services is critical.
- Various factors affect children's likelihood of experiencing growth, health and developmental difficulties, and different levels of surveillance may be appropriate for different children.
- Acknowledgement that there are groups of people who are at risk of experiencing inequitable healthcare and outcomes, including, but not limited to, Aboriginal and Torres Strait Islander Australians, children in out of home care, teenage mothers, families from refugee or culturally and linguistically diverse backgrounds, families who are temporary visa holders, families who live in regional or remote areas, and families experiencing mental health difficulties, learning difficulties, low health literacy, family violence and/or socioeconomic adversity.

Organisations responsible

The Centre of Research Excellence In Newborn Medicine based at the Murdoch Children's Research Institute (MCRI) is responsible for the development and publication of this guideline. Affiliation organisations of all Steering Committee members and authors are also acknowledged as partner organisations. These include The University of Melbourne, Monash University, La Trobe University, The Royal Women's Hospital and Life's Little Treasures Foundation.

Intended users of the guideline

The guideline is mainly intended for health professionals and others involved in the support of children born very preterm and their families, such as early primary health care workers (e.g. GPs and MCHN), childhood educators and disability and community service workers. We anticipate this guideline will also be used by families with children born very preterm.

To whom the guideline applies

This guideline is relevant to all children born very preterm at <32 weeks' gestation, or with birthweight <1500 g if gestation age is unclear, and their caregivers. The follow-up period for the Guideline is from the period shortly before discharge from the neonatal hospitalisation to the commencement of full-time schooling. This guideline focuses on early childhood, recognising this period as a critically important developmental period when the foundations are laid for lifelong health and wellbeing.

What the guideline does not address

This guideline will not focus on:

- Acute hospital care. Continuity of care is vital in achieving the best outcomes for children and families. While this guideline does not cover acute hospital care, opportunities to enhance continuity of care between hospital inpatient services and post-discharge follow-up will be noted.
- Follow-up for school-aged children. It is well established that very preterm birth has the potential to affect children's growth, health and development into adolescence and beyond. However, young children, and their caregivers, have different service needs to older children, as well as different key stakeholders to engage. We intend that a further guideline be developed in the future to provide guidance about growth, health and developmental follow-up for school-aged children and adolescents.
- Evaluation of specific tools that could be used for assessment.
- Evaluation of specific interventions for health or developmental concerns.
- Collection of data for research or benchmarking purposes. While research and benchmarking are important components of advancing knowledge and improving healthcare practices, this guideline focuses specifically on the healthcare needs of the children and families who have experienced very preterm birth.
- Outcomes for siblings of children born very preterm, extended family and kinship groups. We recognise that the experience of very preterm birth within a family can affect all members of the family. While investigation of the impacts of very preterm birth on siblings was beyond the scope of this first edition of the guideline, we hope that a future guideline will incorporate the needs of siblings of children born very preterm, extended family and peers.
- Paediatric palliative care. We recognise children born very prematurely may be born with a life limiting illness and further information can be found in the Paediatric Palliative Care National Action Plan.

Consideration of issues relevant to children and families that may have additional or different needs

Children born preterm and their families who have additional or different needs may be less likely to access follow-up programs [4-6]. The Guideline Development Group (GDG) acknowledged that there are groups of people who are at risk of experiencing inequitable healthcare and outcomes including, but not limited to:

- Aboriginal and Torres Strait Islander Australians
- Children in out of home care

- Families from refugee or culturally and linguistically diverse communities
- Families who are temporary visa holders
- Families who live in regional or remote areas
- Families experiencing mental health difficulties, learning difficulties, low health literacy, family violence, or socioeconomic adversity

Separate recommendations for groups with additional needs such as those listed above are not detailed in the guideline. Services should ensure that adequate resources are available to engage groups less likely to access follow-up care.

Consideration of issues relevant to Aboriginal and Torres Strait Islander peoples

Issues relevant to Aboriginal and Torres Strait Islander peoples have been addressed in this guideline through engagement with Aboriginal and Torres Strait Islander representatives as members of the GDG. These members provided their experience and knowledge of Aboriginal and Torres Strait Islander people when developing the guideline's guiding principles and recommendations.

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 [7]. 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 [8, 9].

Relevant settings

The recommendations included in this guideline are relevant to the growth, health and developmental follow-up of children born very preterm and recommendations can be provided in all healthcare settings, including community-based health and hospital outpatient settings, public and private sectors, and in early educational, disability and community settings.

Guideline development methods overview

The methods used to develop this guideline are aligned with international gold standard AGREE II criteria and Grading of Recommendations, Assessment, Development and Evaluation (GRADE) designed to meet the comprehensive NHMRC criteria for approval of evidence-based guidelines.

See Methods section for details.

Developing the recommendations

Specific, unambiguous, actionable recommendations were drafted by the GDG based on systematic assessment of the best available evidence, together with consideration of the relevance to the

Australian population, the balance of benefits and harms, the values and preferences of the community and clinicians, based on the GRADE framework.

See Methods section for details.

This guideline integrates a summary of the clinical need for guidance on each topic, the clinic question, the evidence summary (systematic and/or narrative), the recommendation or practice points and a justification developed by the GDG. The full evidence reviews, narrative reviews and GRADE framework supporting the recommendation, where relevant, can be found in the supplementary Administration and Technical Reports (Reports can be found on the Newborn Medicine CRE website: https://www.crenewbornmedicine.org.au/).

Guideline development group members

Chairs

Professor Katrina Williams, Head of Department of Paediatrics, Monash University, Director of Research & Developmental Paediatrician, Monash Children's Hospital, Victoria

Professor Angela Morgan, Director of the NHMRC Centre of Research Excellence in Speech and Language, Head of the Speech and Language group at Murdoch Children's Research Institute, co-director of the Speech Genomic Clinic at the Royal Children's Hospital, Victoria and Professor of Speech Pathology, University of Melbourne

Steering Committee (panel of experts)

Professor Jeanie Cheong, Director of the Newborn Medicine Centre of Research Excellence; Co-group leader of the Victorian Infant Brain Studies Group, Murdoch Children's Research Institute; Consultant Neonatologist, Royal Women's Hospital, Victoria.

Professor Peter Anderson, Leader of the Neurodevelopmental Research Program and Professor of Paediatric Neuropsychology in the School of Psychological Sciences, Monash University; Co-group leader of the Victorian Infant Brain Studies Group, Murdoch Children's Research Institute, Victoria.

Professor Rod Hunt, Financial Markets Foundation for Children Chair of Neonatal Paediatrics; Professor of Neonatal Paediatrics, Monash University; Director of Research, Victoria, Cerebral Palsy Alliance; Consultant Neonatologist, Monash Children's Hospital.

Methods

Professor Philippa Middleton, Perinatal epidemiologist and implementation scientist, South Australian Health and Medical Institute, South Australia

Dr Emily Shepherd, Postdoctoral and NHMRC Research Fellow, South Australian Health and Medical Institute, South Australia

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- Dr Jamie Owen (from Jan 2023)
- Dr Alice Burnett (until Apr 2023)
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Ms Kathryn Schembri (until Sep 2022)
Occupational therapist Royal Darwin Hospital, Darwin, NT

Ms Tracey Stephens (until Nov 2022)
Aboriginal Midwife Coordinator
Monash Health, Melbourne VIC

Representation from relevant stakeholder groups

- Consumers
- Community stakeholders
- Nursing/midwifery
- Neonatology
- General practice
- Paediatrics
- Occupational therapy
- Psychology
- Physiotherapy
- Speech Pathology
- Dietetics

Consumer representation

The following members provided perspectives of people born very preterm and their families, including consumer organisations:

- Ms Amber Bates
- Ms Madeleine Francis

- Mr Leigh Hutchinson

Representation from, and consultation with, Aboriginal and Torres Strait Islander peoples

Ms Tamara Porter and Ms Tracey Stephens provided perspectives from Aboriginal clinical practice and advocacy perspectives.

Management of conflicts of interest

A formal process was followed to identify and manage competing interests among GDG members (Appendix 1.)

A Conflict of Interest (COI) was defined as a financial, organisational or other interest of a member of the GDG that might influence or appear to influence the independent performance of the responsibilities in developing this Guideline. Potential members were asked to declare any conflicts of interest when joining the group and any arising during guideline development.

Conflicts or potential conflicts were managed by a COI Management Group, consisting of a GDG chair, a member of the steering committee, and one or two independent advisors, Ms Deborah Dell (Director, Research Operations, Research Support Services, Monash Health) and/or Dr Nitya Phillipson (Research Governance Lead at MCRI). The independent advisors did not otherwise participate in the guideline development process. The process was guided by the National Health and Medical Research Council Standards and Guidelines for Guidelines, and it applied to all members of the GDG and Steering Committeee. The process is described in detail in Appendix 1.

Approvals sought

This guideline will be submitted for consideration of approval by the NHMRC. Approval is also being sought from other relevant organisations, including Tiny Sparks WA, Life's Little Treasures Foundation, Miracle Babies Foundation, ANZNN, PSANZ, RACGP, NACCHO, Occupational Therapy Australia, Australian Physiotherapy Association, Speech Pathology Australia and the Australian Psychological Society.

Methods

This guideline was developed according to the Australian National Health and Medical Research Council (NHMRC) standards and procedures for rigorously developed external guidelines [10] and according to the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach [11].

The multidisciplinary Guideline Development Group (GDG) was convened by inviting people with professional or lived experience of very preterm birth, caring for children born very preterm, and academics with experience in very preterm birth to participate in the development of the guideline. See 1.11 Guideline Development Group Members for a list of GDG members and their affiliations.

Conflict of interest

Conflict of interest was managed by the Conflict of Interest Management Group (see Introduction and Appendix 3).

Identification of previous guidelines

A systematic literature search was conducted for existing evidence-based clinical practice guidelines (CPG) regarding follow-up care of children born very preterm. The search focused on identifying guidelines at a national or international level from countries or regions with developed neonatal intensive care systems (i.e., Australia, New Zealand, Europe, North America). To be included for consideration in relation to the current guideline, existing guidelines needed to:

- Be published within 5 years of the search (January 2017 to January 2022)
- Be written in English
- Be free to access and adapt
- Report a replicable systematic review search strategy

To meet minimum criteria to be considered an evidence-based CPG: 1) systematic methods needed to be used to search for evidence and 2) there needed to be an explicit link between the recommendations and the supporting evidence. Specific search parameters are listed in Appendix 5.

Summary of findings of guidelines search

The 2017 NICE Guideline (NG72) was the most relevant existing guideline and was considered for adaptation. However, there were some differences between the questions selected by the GDG and those addressed in the NICE guidance. Furthermore, the licensing fees chargeable for an international adaptation of NICE content were a prohibitive barrier to adapting and updating this guideline. It was therefore decided to create a new guideline rather than pursue adaptation.

Clinical question identification, prioritisation and management

Clinical questions were developed by the GDG, and a consensus reached on the clinical questions to be addressed by the guideline. Table 1 lists all questions addressed by this guideline.

A period of public consultation was held during which feedback was provided on the scope, and important questions and critical outcomes of interest. Two hundred and thirty-five respondents provided feedback, on which specific outcomes of interest to consider when answering the two systematic review questions. The GDG then voted to identify outcomes of priority. GDG members were asked to rank each suggested outcome using a 1-9 scale, where 9 was the highest priority (Figure 1). Outcomes rated as 7 or above were considered critical for decision-making and were included in the evidence reviews. The specific outcomes listed in Chapters 1 and 2 were the result of consensus of the GWG.

See Chapter 1 and Chapter 2 for specific outcomes.

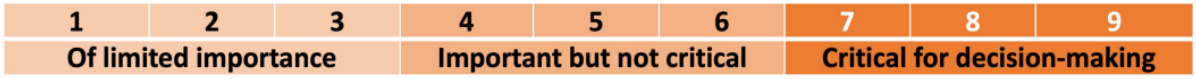

Figure 1 – Rating scale to prioritise clinical questions

Table 2 - Clinical questions and where to find information about them in the Guideline

Question	Guideline Section	Evidence Reviews in Technical Report	Narrative Review in Technical Report
Which aspects of children's growth, health and development and caregivers' wellbeing are affected by very preterm birth?	Background	N/A	N/A
What is the current landscape of follow-up services, early intervention, and developmental supports available for children born very preterm, including social, cultural, and geographical factors affecting access?	Background	N/A	N/A
What factors are important in enabling children born very preterm to have a positive transition to formal schooling?	Background	N/A	N/A
What services do caregivers want for themselves and their children born very preterm from hospital discharge to school entry?	Background	N/A	N/A
Is there evidence that systematic and targeted follow-up after very preterm birth improves child or family outcomes?	Chapter 1	Technical Report 1.3 Characteristics of included studies	Technical Report 1.4 Additional Considerations
What is the impact of biological and environmental factors on growth, health and developmental outcomes for children/families?	Chapter 2	Technical Report 2.5 Characteristics of included studies and Appendix 4	Technical Report 3.6 Characteristics of Included Studies
What assessment methods are appropriate for use when working with children born very preterm?	Clinical Practice Point Recommendations	N/A	N/A

Systematic search for evidence

The PICOT framework was used to explore the components of each clinical question and finalise the selection criteria: population (P), intervention (I), comparison (C), outcomes (O) and timing (T).

These components were used to design the search strategies and to include and exclude studies in the evidence review screening stage. Evidence was identified as the best available and selected to inform recommendations if it fulfilled all the following criteria:

- Current (published within the past 5 years)
- Comprehensive (with the most outcomes relevant to PICOT)
- All selection criteria met.

Inclusion of studies

To decide the evidence to be assessed further, two members of the project management team independently scanned the titles, abstracts and keywords of all records retrieved by the search strategy. Full text articles were retrieved and reviewed, by two independent reviewers, for further assessment if the information in the citation and abstract suggested that the study met the selection criteria and needed to be confirmed. Uncertainty about inclusion at the title and abstract and screening stages was resolved through discussion amongst the reviewers and resolved by a member of the steering committee if required.

Appraisal of the methodological quality/risk of bias of included studies

Methodological quality of the included studies was assessed independently by two reviewers using the JBI Critical Appraisal Checklist for Cohort Studies *(see Technical Report).*

Data extraction

According to the selection criteria, data was 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.

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 data collected was not appropriate for meta-analysis.

Narrative reviews

Narrative evidence reviews were completed for:

- Questions that were less suited to a systematic evidence review format
- Lower prioritised questions
- Situations in which insufficient evidence identified for a question where an evidence review was conducted.

Narrative reviews were informed by research and prepared by the project management team. Reviews included key information to answer the clinical questions and to guide the GDG to draft consensus recommendations or practice points.

Quality/certainty of the body of evidence using GRADE evidence profiles

GRADE evidence profiles/tables were prepared for the evidence synthesised for Questions one and two (see technical report). For each outcome for both questions, a certainty rating was documented based on consideration of the (1) number and design of the studies addressing the outcome, and on judgments about the (2) risk of bias of the studies and/or synthesised evidence, (3) inconsistency, (4) indirectness, (5) imprecision, and any other considerations that may have influenced the quality/certainty of the evidence. The overall quality/certainty of evidence reflected the extent to which our confidence in an estimate of the effect was adequate to support a particular recommendation with assessment of the quality/certainty of a body of evidence overall reported as one of four grades [11] (Table 3).

Table 3 - GRADE Certainty of Evidence Assessment

Grade	Definition
High	We are very confident that the true effect lies close to that of the estimate of the effect.
Moderate	We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different from the estimate of the effect.
Low	Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.
Very Low	We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

It should be noted that in the GRADE approach to quality of evidence:

- Randomised trials without important limitations provide high quality evidence
- Observational studies without special strengths or important limitations provide low quality evidence

Drafting recommendations

Specific, unambiguous, actionable recommendations were drafted. In developing and interpreting the recommendations in this guideline, evidence was assessed and considered along with multidisciplinary health professional expertise and consumer perspectives.

Types and wording of recommendations

In developing the recommendations in this guideline, evidence was assessed and considered by multidisciplinary health professional experts and consumers. There are four key elements to each recommendation

- Type
- Wording
- Certainty of evidence
- Grade of recommendation.

Recommendation type can be either evidence-based (EBR) or consensus (CCR). Clinical practice points (CPP) are also included to assist with implementation of the recommendations. For evidence-based recommendations (EBRs) and consensus clinical recommendations (CCRs), the terms “should”, “could” and “should not” were used to reflect the interpretation of the quality/certainty of the body of evidence and judgements of the multidisciplinary and consumer GDG. The word “should” was used in the recommendations where the GDG judged that the benefits of the recommendation would exceed the harms. The word “could” was used when the quality of evidence was limited or the available studies did not clearly demonstrate advantage of one approach over another, or when the balance of benefits to harm was unclear. The words “should not” were to used when there was either a lack of appropriate evidence, or the harms were judged to outweigh the benefits but there were no ‘should not’ recommendations developed as part of this guideline.

Certainty of evidence (very low to high) for EBRs reflects the quality and relevance of the evidence, based on information about the number and design of studies addressing the outcome, judgements about the quality of the studies and/or synthesised evidence, across the risk of bias, inconsistency, indirectness, imprecision and any other quality considerations; key statistical data; and classification of importance of outcomes *(see Methods).*

The grade (strength) of EBRs (strong recommendation or conditional recommendation) was determined by the GDG based on comprehensive consideration of all elements of the framework (National Health and Medical Research Council, 2009): desirable and undesirable effects, balance of effects, equity, acceptability and feasibility *(see Methods).*

Due to a lack of evidence only CCRs were developed as part of this guideline. CPPs were included to provide guidance for implementation issues such as safety, side effects and risks. (Table 1).

For more details see the Administrative and Technical Reports.

Discussion of recommendations in GRADE evidence-to-recommendation framework

For question 1, The GRADE evidence-to-recommendation framework was used to document the discussion, judgements and decisions to reach consensus through assessment of the evidence, clinical expertise and the person's preference for factors such as: the balance of benefits and harms of the intervention; certainty of the evidence; resource requirements; equity; acceptability; feasibility; subgroup considerations; implementation considerations; monitoring and evaluation; and research priorities.

For question 2, the GRADE evidence-to recommendation framework was not considered appropriate as the guideline development group did not intend to make specific recommendations on individual risk factors but rather consider how the presence of various risk factors may influence structured follow-up care.

For some questions, the evidence review found a lack of evidence. The GDG acknowledges that a lack of evidence is not evidence of the lack of an effect. This consideration is reflected in the strength assigned to recommendations on interventions that are not support by evidence.

Public consultation

Public and target consultation of the drafted guideline was opened on August 21st for a period greater than thirty days in accordance with the legislative requirements of the National Health and Medical Research Council Act 1992 as outlined in the NHMRC standards for guidelines [10].

External review

This guideline was reviewed independently by relevant professional experts, professional colleagues, and societies and through public consultation. Two independent AGREE II assessments were also be conducted.

After 5 years the guideline panels will be reconvened and the guideline updates as per NHMRC processes.

Background

Introduction

Over 3000 babies are born very preterm (VP; before 32 weeks of gestation) in Australia each year [1]. At this critical stage in prenatal development, all major organ systems are immature, and babies require intensive medical care to survive. Such early birth has the potential to affect children's short- and long-term growth, health and development, and the wellbeing and mental health of their caregivers. Despite their perilous early days, it is important to acknowledge that many children born VP have age-appropriate long-term development and many caregivers experience comparable quality of life to caregivers of full-term children in the longer-term [12]. Nevertheless, VP birth remains a significant risk factor for growth, health and developmental difficulties for children, and mental health difficulties for caregivers, which merit clinical surveillance and support.

Definitions and Epidemiology of Prematurity and Birthweight

Preterm birth, or birth before 37 completed weeks of gestation, is a major global health issue [13]. Preterm birth can be further categorised into moderate to late preterm birth (MLP; 32-36 weeks' gestation), very preterm birth (VP; <32 weeks' gestation), and extremely preterm birth (EP; <28 weeks' gestation), and earlier birth is associated with a higher chance of mortality and long-term growth, health and developmental morbidity. Prior to the widespread use of antenatal ultrasound to assess fetal development, birthweight was used as the primary indicator of gestational maturity. Birthweight <1500 g is classified as "very low" (VLBW) and birthweight <1000 g is classified as "extremely low" (ELBW). It is important to note, however, that birthweight and gestational age are not entirely concordant, as some babies are smaller or larger than is typical for their gestational age. Of the nearly 300,000 live births in Australia in 2020, 3,237 babies, or around 1.1%, were born very preterm [1]. Due to their physical immaturity at birth, these babies require specialist hospital care in order to survive. Advances in neonatal intensive care have brought improvements in survival for babies born VP over time, with more than 90% now surviving to discharge home from hospital in Australia and New Zealand [14]. However, these babies have substantially increased risks of long-term growth, health and developmental difficulties compared with babies born at term, and consequently are the focus of this guideline.

The Impacts of Very Preterm Birth on Child Growth, Health and Development and Parent Wellbeing

Short-term Impacts of Very Preterm Birth

Birth in the VP period exposes babies to the extrauterine environment prematurely, which can disrupt the intended trajectory of developmental processes for major organ systems, including the brain, lungs, heart, immune, and sensory systems. Medical complications are more common in babies born earlier in gestation. These complications do not occur in isolation but are often interrelated, and many are associated with longer-term growth, health and developmental outcomes.

An enormous amount of brain development occurs across gestation, and beyond. VP birth is associated with a risk of direct injuries to the brain, including intraventricular haemorrhage (IVH) and periventricular leukomalacia (PVL). IVH is defined by bleeding in or around the ventricles and typically occurs in the first days of life. Its severity can be categorised into grades, with grades III and IV

indicating severe injury [15]. More severe IVH affects around 4% to 12% of VP infants in high-resource settings [16]. PVL is injury to the white matter surrounding the ventricles, with cystic PVL being the most severe form. The prevalence of cystic PVL is around 2-6% [16]. More subtle brain injuries and disruptions to brain development are also likely to occur after VP birth and to shape longer term development [17], but these are less visible on cranial ultrasound, which is the current clinical standard for brain imaging in the neonatal intensive care setting.

Respiratory difficulties are a key medical concern for babies born VP, as VP birth disrupts normal lung development and the body's ability to produce surfactant needed to inflate and deflate the lung is limited until 34-35 weeks' gestation [18, 19]. Bronchopulmonary dysplasia (BPD; also known as chronic lung disease, or CLD) is defined as a persistent need for oxygen support at 36 weeks' gestation, although definitions have evolved over time. It is a high-prevalence condition, affecting a quarter of VP and around 40% of EP infants [20, 21]. Postnatal corticosteroids are an effective treatment for BPD [22] but can bring their own risk for harms over the short- and long-term [e.g., [23]].

Other complications for babies born VP can include serious inflammatory and immune conditions. Necrotising enterocolitis (NEC) is one such inflammatory condition and occurs when the intestinal lining becomes inflamed and dies. This can affect around 8% of babies born EP and a much smaller proportion of those born at 28-31 weeks (1%), but it is a key cause of mortality and morbidity, and up to half of babies with NEC can require surgical treatment [14]. Babies born VP are also vulnerable to major infections such as sepsis, which can be either early onset (presumably maternally acquired) or late onset (presumably post-natally acquired). These infections can affect around 10% of babies born VP overall [14].

VP birth also brings well-recognised risks for the vision and hearing systems. Retinopathy of prematurity (ROP) is the best-known visual complication and is a key risk factor for long-term vision impairments after preterm birth [24]. More severe ROP (stage 3+) may affect around 8% of babies born VP [14]. Being a patient in neonatal intensive care is also a recognised risk factor for sensorineural hearing loss, affecting 1-8% of babies born VP [25].

Longer-term Impacts of Very Preterm Birth

Much research has documented the long-term impacts of VP birth on children and, to a lesser extent, their families. As a group, children born VP are at higher risk of difficulties in a range of growth, health and developmental domains compared with children born full-term, which are outlined in this section. As noted above, however, there is substantial heterogeneity in the outcomes for individual children, with children displaying various patterns of strengths and weaknesses and many children having positive developmental journeys.

Physical Health Outcomes for Children born Very Preterm

VP birth is associated with a range of other long-term physical health outcomes. Growth, as reflected in weight, height, head circumference, and body mass index (BMI) is typically lower in children born VP compared with term-born peers [26, 27]. An increased risk of respiratory conditions such as asthma or wheezing is also reported for children born VP compared with those born full term [28]. Gestational age at birth is also inversely associated with the likelihood of being rehospitalised in general, for both

respiratory infections and other types of infections [29, 30]. Although infrequent, major sensory impairments are serious outcomes that are more common in VP than in term-born children, as are milder visual and hearing problems [24]. Cardiovascular health can be affected, with increased blood pressure reported in adolescents born EP/ELBW [31] and in adults born VLBW [32].

Developmental Outcomes for Children born Very Preterm

A substantial amount of research has identified a heightened chance of 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 neurodevelopmental disability or impairment (hereafter termed NDI). 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 NDI status changes for over a third of children born VP from 2 to 8 years [33]. Cognitive impairment is the most frequently identified component of NDI in children born VP (up to 10%) [34]. VP birth affects overall cognitive functioning (as indicated by IQ), and more nuanced aspects of cognition such as attention, executive functioning (including working memory), and visual-spatial skills [35-37]. For instance, at the group-level, VP birth is associated with a reduction in average IQ of about 0.8-0.9 SD or 12-13 IQ points compared with full term children [35, 36]. Language and communication delays are common after VP birth [38]. Up to half of children born EP may have at least a mild delay (scores 1SD below mean of term born controls) in language development at 2 years [39], and the vulnerability for language skills after VP birth persists into at least childhood and early adolescence [40]. While CP can be a severe adverse motor outcome of VP birth, children born VP also face a higher risk of non-CP motor difficulties in areas such as coordination, balance, visuomotor integration, and motor control, including those meeting criteria for developmental coordination disorder [41]. With regards to feeding, a recent meta-analysis indicated that the overall prevalence of difficulties with oromotor eating and feeding behaviours is increased among children born preterm (not restricted to those born VP), although the quality of the evidence was considered very low [42].

Finally, children born VP are more likely than their term-born peers to have difficulties with social, emotional, and behavioural functioning particularly in the areas of hyperactivity/inattention, internalising (e.g., anxiety, depression symptoms), and peer functioning [43, 44]. VP birth is also a recognised risk factor for clinical diagnoses of attention deficit hyperactivity disorder (ADHD), anxiety disorders, and autism spectrum disorder (ASD) [45-47].

Sleep Outcomes for Children born Very Preterm

Sleep is essential for optimal physical health, cognitive functioning, and emotional-behavioural wellbeing and is often a key concern for families with young children. Sleep patterns develop from infancy to adulthood, and sleep difficulties can arise due to physical health causes or behavioural needs. Although less well-studied than some other outcomes, there is a small body of literature suggesting very preterm birth may affect at least some aspects of sleep [48]. A large national register study from Sweden indicated that gestational age is negatively associated with the risk of sleep-disordered breathing across infancy, childhood, and adulthood [49].

Quality of Life

Health-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]. 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 young people born VP, particularly those without major disability [53], and their caregivers [12].

Impacts on Parental Wellbeing

The experience of VP birth is typically highly distressing for caregivers, with both mothers and fathers reporting greater symptoms of anxiety and depression than caregivers of term-born babies in the first months of their children's lives [54]. After NICU discharge, caregivers of infants born VP have increased rates of anxiety, depression, and post-traumatic stress symptoms [55], although encouragingly, the prevalence of clinically significant mental health problems appears to diminish over the early childhood years [56].

Follow-up Care after Very Preterm Birth

The Current Landscape of Follow-up Care in Australia

In high-income countries around the globe, it has long been recognised that post-discharge follow-up care for high-risk newborns, such as those born VP, is essential [57, 58]. This reflects an acknowledgment that, while as a group these children are known to have increased risks of difficulties, an individual child's long-term outcomes cannot be known with great confidence at the time of hospital discharge, and difficulties may emerge at different points in children's development. Closer growth, health and developmental follow-up, sometimes termed surveillance, is therefore warranted than for children born healthy or full-term to identify needs arising and implement appropriate intervention. For children born VP, however, access to developmental follow-up can be dependent on geographic location and resources of specific centres. Children from rural areas, and from marginalised, socio-economically disadvantaged groups, and culturally and linguistically diverse backgrounds may be less likely to access follow-up programs, and subsequent early intervention [4-6]. 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.

In Australia, many infants born 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, and this data is collated by the Australian and New Zealand Neonatal Network [14]. This includes a formal developmental assessment of cognition, motor and language, paediatric medical assessment, and assessment for cerebral palsy. A high proportion of eligible children attend follow-up between 18 and 42 months' corrected age, however, around 15%

do not receive follow-up in the toddler period. Evidence from Australian longitudinal research suggests that rates of neurodevelopmental disabilities are higher in children whose families have more difficulty attending follow-up appointments within the research context [59]. In addition, many children born 28-31 weeks do not currently have access to structured preterm-specific follow-up care in Australia, and these babies account for over 60% of the babies born VP each year [1].

Assessments in the toddler period are important in identifying areas of developmental difficulty and facilitating appropriate support for children and families, such as referral to early intervention services [60] which have been shown to improve children's outcomes up to preschool age [61]. However, such early assessments can provide only an indication of longer-term outcomes, given the protracted developmental course of many important functions [e.g., [62]] and lack of good-quality evidence for early intervention programmes [61]. Currently limited evidence suggests the benefits of early intervention may not be sustained over time [61]. Follow-up later into childhood is essential to monitor the emergence of further skills and abilities but is not yet a widely available standard of care.

Caregivers' Values and Preferences Regarding Follow-up Care

A narrative review of the literature indicated that there are many areas of priority for families and health professionals with respect to outcomes of preterm birth. Although there is much research into the long-term outcomes of very preterm birth, traditionally researchers and clinicians have selected outcomes to be studied, rather than families who have experienced very preterm birth [63, 64]. Caregivers of young children born <29 weeks' gestation often report concerns related to their child's development and physical health [65]. Luu and Pearce (2022) also highlight the importance of incorporating a child's positive characteristics, such as their strengths and qualities, into the clinical understanding of their situation.

A recent publication reported 21 priority childhood outcomes for babies born preterm or hospitalised developed through the International Consortium for Health Outcomes Measurement [66]. This study, which involved an international working group of healthcare professionals and patient representatives, identified the following outcomes as consensus priorities:

Table 4 - International Consortium for Health Outcomes Measurement - Childhood outcomes for babies born preterm or hospitalised (Schouten et al.).

Physical functioning	**Mental functioning**	**Social functioning**
• Feeding, nutrition, and growth • Pulmonary function • Motor function • Disability • Survival • Readmission • Pain • Sleep • Hearing • Vision	• Neurodevelopment • Cognition • Behaviour • Depression • Anxiety	• Impact on family • Communication • Health-related quality of life • Relationships with others • Social functioning • Schooling

Table developed from outcomes detailed in Schouten et al. [66]

While there is only a small amount of literature directly examining caregiver opinions about post-discharge outcomes for children born very preterm, findings to date consistently identify both physical and developmental concerns as important areas to caregivers. However, there is little information about whether outcomes are valued differently by groups of people who have different levels of social advantage.

More research has been conducted involving people who have experienced neonatal hospital care because of preterm birth broadly and other high-risk neonatal conditions. A systematic review of qualitative literature found that many outcomes are discussed by former neonatal patients, caregivers, and health professionals [67]. This review included people with experience of neonatal care generally and examined outcomes discussed both during the neonatal hospitalisation and afterwards. The review identified the following outcome domains:

Table 5 - Outcome Domains (Webbe et al)

Organ systems	Holistic outcomes	Parent-focused outcomes
• Cardiovascular • Respiratory • Gastrointestinal • Neurological • Genitourinary • Infection • Skin • Developmental	• Survival • Growth • Pain • Suffering • Normality • Other outcomes	• Parental support • Other outcomes
Social outcomes	**Healthcare delivery outcomes**	**Economic outcomes**
• Psychiatric outcomes • Relationships with others • Other outcomes	• Healthcare workers – knowledge and competence • Healthcare workers – communication • Other outcomes	• Healthcare utilisation • Other outcomes

Table developed from outcomes listed in Webbe et al. [67]

Webbe and colleagues found that the most frequently discussed outcomes were "parental support" and "healthcare workers – communication", reported in about half of the studies reviewed. The primary difference reported between stakeholders was that former patients of neonatal care "discussed outcomes relating to the genitourinary, surgical, developmental and pain outcome domains more than would be expected by chance" [67].

In summary, family wellbeing, the quality of relationships with clinicians, as well as children's health and functional outcomes, appear to be important outcomes to people who have experienced neonatal care.

Supporting Children born Very Preterm to Transition Successfully to Formal Schooling

Commencing 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 [68]. 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 five areas important for school readiness [69, 70]. 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 [69, 70]. Having two or more areas of vulnerability is predictive of later educational difficulties [69]. Even amongst children not already identified as having a physical or intellectual disability or other special needs, 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 [71]. 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.

The National agreement on closing the gap aims to reduce socio-economic disadvantage on Aboriginal and Torres Strait Islander Australians [7]. 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 development of the child.

Chapter 1: Structured Follow-up

1.1 Clinical practice gaps, uncertainties and need for guidance

There are currently inconsistencies in the follow-up services available to children born very preterm across Australia. Consistent guidance is required to ensure optimal outcomes for these children and their families.

1.2 Clinical question

Structured Follow-up Care	**Is there evidence that systematic and targeted follow-up after very preterm birth improves child or family outcomes? ***
*PICOT format – Population (P): infants born <32 weeks' gestation; Intervention (I): structured, preterm-specific post-hospital follow-up care, Comparison (C): compared with any other follow-up care (which could include no follow-up), Outcome (O): improve health, developmental, or emotional/behavioural outcomes for children, or mental health for caregivers (see list of specific outcomes Table 6), Timing (T) at any later time	

Table 6 - Specific Outcomes

Domain	**Subdomain**	**Specific outcomes of interest**
Physical	Growth and nutrition	• Height/length/weight/head circumference • BMI • Body composition
	Respiratory	• Asthma • Respiratory tract infections • Croup
	Cardiovascular	• Elevated blood pressure
	Infection	• Gastrointestinal • Otitis media
	Sensory functioning	• Vision • Hearing • Blindness • Deafness
Sleep	Sleep	• Sleep problems, including sleep apnoea
Developmental	General development	• Neurodevelopmental impairment (a composite of sensory, motor, and/or cognitive impairments)
	Cognition	• Early cognitive development • General cognition/IQ • Attention • Working memory/ executive function • Visuospatial skills
	Feeding	• Swallowing • Functional feeding skills • Feeding disorders

Domain	Subdomain	Specific outcomes of interest
	Language and communication	• General language function or delay • Receptive language • Expressive language
	Motor	• Cerebral palsy • Developmental coordination disorder (or high-risk of DCD) • General motor function or delay • Fine motor function or delay • Gross motor function or delay
	Behaviour, emotions, and mental health	• General behaviour difficulties • Hyperactivity/externalising • Anxiety/internalising • Autism spectrum disorder • Attention deficit hyperactivity disorder • Other psychiatric disorders • Trauma • Adaptive behaviours
	Social skills	• Friendships • Interpersonal relationships
	School readiness	• Pre-academic skills
Quality of Life	Overall quality of life	• Child's quality of life
		• Family's quality of life
Family	Parental wellbeing and mental health	• Anxiety • Depression • General stress • Post-traumatic stress
	Parental knowledge of child development	
	Parenting	• Parenting behaviour • Parenting confidence • Parent self-efficacy
	Access to services	• Barriers to accessing services (follow-up and early intervention)

1.3 Summary of evidence review

The systematic review identified one study that focused on follow-up that was structured (i.e., had a particular schedule of appointments rather than ad hoc interactions between families and health professionals) and was offered in the window between the time of discharge and when each child turned 6 years of age (as a proxy for school entry) [72] *(See Technical Report).*

GRADE certainty of evidence was very low for this study. The rates of NDI and CP were not different between conventional follow-up and structured follow-up, however formal diagnoses of NDI and CP were earlier when structured follow-up occurred (6 vs. 14 months corrected age) [72].

1.4 Summary of narrative review

Due to the minimal evidence on which to base recommendations, supporting evidence was considered from publications 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 *(See Technical Report).*

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 [14, 73-75]. However, there is considerable variability in the timing and type of follow-up programs reported [58, 76]. In Australia, children born <28 weeks' gestation ("extremely preterm") or <1000 g ("extremely low birthweight") may be offered review until 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.

Many leading clinician researchers around the world have recommended that clinical follow-up should continue throughout childhood because difficulties may emerge later in development, particularly in cognition and behaviour [57, 74, 77]. Formal cognitive assessment shortly before the start of formal schooling at 4-5 years corrected age is a common practice and can be utilised for planning future education needs. Early assessments of cognitive development using scales such as the Bayley Scales of Infant and Toddler Development may not be indicative of later cognition [78], while assessments at 4-5 years are robust and reliable [79] and have the potential to become a major timepoint for the planning of education needs. There is a major opportunity for follow-up care to become more family-centred, by tailoring more accessible information and supports to the needs of individual children and their families to promote health, development and wellbeing [58].

1.5 Evidence to recommendation statement

The consensus-based recommendations are needed to raise awareness for the need for structured, preterm specific follow-up care to improve outcomes for children born very preterm 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. While evidence was limited in the evidence review, the reported practice and of adverse outcomes from research, included in the narrative review, and experience of the committee suggested that consistency and clarity of follow-up services is needed in Australia.

1.6 Recommendations

Consensus-based Recommendation 1

Structured, preterm-specific post-discharge follow-up care should be offered to children born very preterm and their caregivers.

Clinical Practice Points

*In providing structured, **preterm-specific** follow-up care, service providers should consider the following practice points:*

- This proposal offers a *minimum* set of contacts and priorities; services and clinicians should offer more support as they consider appropriate.
- Follow-up should be provided in a flexible way to meet the needs, priorities and concerns of each individual child and caregivers.
- Children with very complex conditions / specific needs may need additional specialised follow-up e.g., retinopathy of prematurity monitoring, post-surgical follow-up.
- Corrected age should be used when considering a child's growth, health, and development.
- Involve key caregivers outside the family, such as early childhood professionals, to ensure a holistic view of children's wellbeing/functioning.
- Children born very preterm, and their caregivers should have post discharge follow-up care planning initiated by the treating NICU and transition to an appropriate follow-up service with a formal handover (ideally person to person whenever possible).
- 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.
- Clinicians should be appropriately trained/upskilled to assess the priority areas listed in these guidelines.
- Establishing strong professional links with larger teams of expertise may help facilitate training and maintenance of professional development.
- 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 a hybrid (e.g., telehealth contacts facilitated with a local healthcare professional) based on families' preferences, clinical needs, and any other relevant factors.

Consensus-based Recommendation: Follow-up Schedule

Table 7 - Follow-up Schedule

Priorities	Shortly post-discharge (7-10 days)	6w post-discharge	3-4mo CA	6mo CA [ab]	8-9mo CA	12mo CA [c]	18mo CA [e]	24mo CA	2.5y CA [a]	4-5y CA [f]
Physical Health										
General health (incl. respiratory)	+	+ Vaccination Schedule[h]	+		+ Vaccination Schedule[h]	+	+	+		+ Cardiovascular (BP) Respiratory (asthma)
Growth	+	+	+		+ Height/BMI)/ Nutrition (incl. Feeding)	+ (Height/BMI)/ Nutrition	+ (Height/BMI)/ Nutrition	+ (Height/BMI)/ Nutrition		+ (Height/BMI)/ Nutrition
Sensory		+ Vision Hearing	+		+	+ Vision Hearing	+	+		+ Vision, Hearing
Developmental										
Feeding	+ Lactation support	+	+ Plan for starting solids			+				
Sleep	+	+	+		+	+				
Behaviour, Developmental progress, and support	+	+	+ Early detection of infants at high-risk of CP [c].		+ (language/ communication/ motor)	+ (language/ communication/ motor)	+ (language/ communication/ motor)	+ Formal developmental assessment [d] (cognition/language/ communication, motor), screen for emotional-behavioural concerns		+ Formal cognitive assessment [d] Pre-academic skills, Behaviour, Language/communication, Motor skills
Quality of Life										
For child and family						+				+
Family										

Wellbeing, Mental health[g],	+	+	+		+	+	+	+		+
Resources/ Information needs[i]	+ incl. milestones for CA	+	+		+	+	+	+		+

Abbreviations: mo: months, y: years, CA: corrected age, BMI: body mass index, BP: blood pressure

[a] Review if parental concerns or clinical need

[b] Telehealth check-in may be advised

[c] Expertise in early detection of CP. Novak et al. 2017 https://jamanetwork.com/journals/jamapediatrics/article-abstract/2636588

[d] Face to face assessment suggested for formal developmental assessment at 24 months corrected age and formal cognitive assessments at 4-5 years corrected age.

[e] Telehealth check in with face to face appointments if indicated

[f] Timing of contact to consider child's likely commencement of formal schooling.

[g] Including parent-child attachment

[h] Vaccinations administered via chronological age

[i] Consider socio-economic background assessment of family when considering information needs.

1.7 Clinical considerations for implementation of the recommendations

There are important considerations in planning for the adoption of this guideline. 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 weighed the risk versus benefit of recommendations. The factors considered can be seen in Table 8 and further detail found in the Technical Report.

Table 8 - Evidence to decision framework judgements

Implications for Clinical Practice	Summary of judgements and comments from GRADE Evidence to Decision Framework
Problem	The GDG has identified that the potential health, developmental, and caregiver impacts of very preterm birth are a major priority for families and the community. Please see background of guideline for more detail of the narrative review conducted.
Desirable Effects	The GDG considers that the benefits of offering structured, preterm-specific follow-up care would be at least moderate and likely large for some families, as children born very preterm are known to be at increased risk of adverse outcomes and currently have access to variable follow-up care.
Undesirable Effects	While we have no direct evidence, the GDG considers that harms or undesirable effects of offering structured, preterm-specific follow-up care are likely to be small (e.g., may be a source of anxiety for families; attending appointments can be costly and burdensome depending on families' situations). Families would be free to choose whether to engage with the care that is offered.
What is the overall certainty of the evidence of effects?	Outcomes of interest were captured in a single study. The outcomes included were a composite of neurodevelopmental impairment measure, cerebral palsy, visual impairment and hearing impairment. Evidence certainty was very low about the effect of different kinds of clinical follow-up for all outcomes.
Values	The GDG considered that there was possibly important uncertainty or variability in how caregivers and those born very preterm value different outcomes. This is because the existing literature often combines perspectives of people who have experienced very preterm with those who have experienced other neonatal conditions (i.e., is indirect to our population of interest), and there has been little explicit investigation of perspectives of consumers with socioeconomic disadvantage.
Balance of effects	Overall, the GDG judged that the balance of benefits and harms favours offering structured, preterm-specific follow-up care for children born very preterm compared with the current variability of care, which may include no routinely available follow-up care
Equity	While we have no evidence, the GDG considers that offering structured, preterm-specific follow-up care would probably increase health equity. Equity

	factors should be considered in tailoring services to local contexts and resourcing them appropriately.
Acceptability	The GDG considers that offering structured, preterm-specific follow-up care is acceptable to key stakeholders (families who have a child born very preterm and clinicians).
Feasibility	The GDG believes that offering structured, preterm-specific follow-up care is feasible for consumers and individual clinicians but will require additional resourcing in some settings (e.g., funding tailored to the requirements of the consumer and clinicians).

Note: no economic evaluations of different clinical follow-up models were identified in the systematic review of the literature related to Question 1. Using GRADE guidance, we elect to not consider resource use in forming recommendations, given a lack of reliable data.

The Guideline Development Group (GDG) acknowledge that the implementation of guideline recommendations may be difficult in areas with a shortage of resources (particularly in relation to speech therapy, occupational therapy and genetic counselling services in many states and territories). The GDG recommends that implementation may be supported by services having a flexible approach in providing follow-up based on families' preferences, clinical needs, early assessment findings and other relevant factors including appropriate resourcing. The GDG is aware that many regions may not have access to specific professions and therefore encourage clinicians to be appropriately trained/upskilled to assess the priority areas listed in these guidelines. Further recommendations regarding implementation can be found in the implementation plan.

The GDG discussed the need for guidance 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 guidance based on the GDG's experience only (see Appendix 6). Appendix 6 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.

Chapter 2: Risk/Resilience Factor Recommendations

2.1 Clinical practice gaps, uncertainties and need for guidance

Children born very preterm are at risk of poorer growth, health and developmental outcomes. This review was undertaken to identify whether recommendations for follow-up should be modified for children who are known to be at an increased risk of poorer growth, health and developmental outcomes, due to additional medical and/or socioeconomic factors.

2.2 Clinical question

Risk/Resilience Factors	**What biological and environmental factors influence health and developmental outcomes for children born very preterm and their caregivers ***
*PICOT format – Population (P): infants born <32 weeks' gestation; Intervention (I): do medical: gestational age, sex, small-for-gestational age status, brain abnormalities, sepsis, retinopathy of prematurity, necrotising enterocolitis, antenatal corticosteroids, postnatal corticosteroids, bronchopulmonary dysplasia, neonatal surgery, neonatal seizures and social/environmental; socioeconomic status, parental mental health, access to breastmilk in the neonatal/infant period, adverse childhood experiences, geographical remoteness, culturally and linguistically diverse background; Comparison (C): compared with not having the complication/exposure, Outcome (O): affect later health or developmental or emotional/behavioural outcomes for children, or mental health for caregivers, Timing (T) at any later time.	

Table 9 - Specific Outcomes for Question 2

Domain	**Subdomain**	**Specific outcomes of interest**
Physical	Growth and nutrition	• Height/length/weight/head circumference • BMI • Body composition
	Respiratory	• Asthma • Respiratory tract infections • Croup
	Cardiovascular	• Elevated blood pressure
	Infection	• Gastrointestinal • Otitis media
	Sensory functioning	• Vision • Hearing • Blindness • Deafness
Sleep	Sleep	• Sleep problems, including sleep apnoea
Developmental	General development	• Neurodevelopmental impairment (a composite of sensory, motor, and/or cognitive impairments)
	Cognition	• Early cognitive development

Domain	Subdomain	Specific outcomes of interest
		• General cognition/IQ • Attention • Working memory/ executive function • Visuospatial skills
	Feeding	• Swallowing • Functional feeding skills • Feeding disorders
	Language and communication	• General language function or delay • Receptive language • Expressive language
	Motor	• Cerebral palsy • Developmental coordination disorder (or high-risk of DCD) • General motor function or delay • Fine motor function or delay • Gross motor function or delay
	Behaviour, emotions, and mental health	• General behaviour difficulties • Hyperactivity/externalising • Anxiety/internalising • Autism spectrum disorder • Attention deficit hyperactivity disorder • Other psychiatric disorders • Trauma • Adaptive behaviours
	Social skills	• Friendships • Interpersonal relationships
	School readiness	• Pre-academic skills
Quality of Life	Overall quality of life	• Child's quality of life • Family's quality of life
Family	Parental wellbeing and mental health	• Anxiety • Depression • General stress • Post-traumatic stress
	Parental knowledge of child development	
	Parenting	• Parenting behaviour • Parenting confidence • Parent self-efficacy
	Access to services	• Barriers to accessing services (follow-up and early intervention)

2.3 Summary of evidence review

A total of 129 studies were included in the evidence review. A summary of the risk/resilience factor outcome combinations is presented below. For more detail, please see the Technical Report.

Table 10 - Risk/Resilience Factors Association with Outcomes Summary

Risk/Resilience Factor	Physical	Sleep	Developmental	QoL	Access to follow-up care
GA (lower)	↓	○	↓	↓	↑
Sex (male)	↓	↑	↓	○	○
SGA	↓	○	↓	○	↓
Brain injury	↓	○	↓	○	○
Sepsis	○	○	↓	○	○
ROP	○	○	↓	○	○
NEC	↓	○	↓	○	○
ANS	○	○	↑	○	○
PNS	↓	○	↓	○	○
BPD	↓	○	↓	○	○
Surgery	○	○	↓	○	○
Seizures	↓	○	↓	○	○
SES (lower)	↓	○	↓	↓	↓
No breastmilk in the infant/neonatal period	○	○	↓	○	○
ACE	○	○	↓	○	○
Remoteness	○	○	○	○	↓
CALD	↓	○	↓	↓	↓/↑

↓ risk/resilience factor negatively affects the outcome, ↑ risk/resilience factor improves the outcome, ○ no association found. Acronyms: GA: gestational age, SGA: small for gestational age, ROP: retinopathy of prematurity, NEC: necrotising enterocolitis, ANS: antenatal corticosteroids, PNS: postnatal corticosteroids, BPD: bronchopulmonary dysplasia, SES: socioeconomic status, ACE: adverse childhood experiences, CALD: culturally and linguistically diverse.

Gestational age (GA)

Lower GA was associated with an increased risk of growth failure [80-82], elevated blood pressure [83], hearing loss [84], neurodevelopmental impairments [80, 85-89], general language delay [90], autism spectrum disorders [91], low health-related quality of life for children [92], and lower GA was associated with an increased attendance at high-risk follow-up services [93].

Sex

Males exhibited a higher rate of respiratory tract infections [94, 95], NDIs [86, 89, 96-105], lower IQ/general cognitive [104, 106], cerebral palsy [107, 108], general motor function delay [107] DCD [109], early cognitive delay [99, 110], general language function delay [80, 111], low receptive [112] and expressive language skills [112], gross motor delay [112], general behavioural difficulties [113], autism spectrum disorders [91, 106, 114], attention deficit hyperactivity disorders [106], and poor quality of life [92, 106] compared to females.

Males were found to have a lower risk of growth failure (defined as birth weight below the 3rd percentile) [115], sleeping problems [116] and fine motor delay [117] compared to females.

Small for gestational age (SGA)

Children classified as SGA demonstrated a significantly higher likelihood of experiencing growth failure [82, 115], NDIs [105, 107, 118], and developmental coordination disorders (DCD)[109]. Families of children with SGA were more likely to have an increased access to health and developmental services [93].

Brain abnormalities

Grade III/IV IVH was associated with an increased risk of NDI [86, 97, 101, 102, 107, 118-121], early cognitive delay [107, 121], general language delay [121], cerebral palsy [107, 121-123], general motor function delay [107, 124], and gross motor function or delay [124].

Children with PVL had an increased risk of experiencing physical growth failure [125], NDI [86, 88, 101-103, 107, 119, 126], early cognitive delay [107, 127], cerebral palsy [107, 123, 128], and delays in general motor function [107, 124, 127] and gross motor function issues [124].

Children affected by IVH grade III/IV and/or PVL are at an increased risk of experiencing physical growth failure [80, 115], NDI [80, 89, 96, 129-133], cerebral palsy [80, 132, 134, 135], early cognitive delay [80, 127, 134, 136], lower IQ/general cognitive ability [135, 137-140], lower independent feeding ability [134], delays in general language [80, 127] and motor function delay [127, 134].

Sepsis

Neonatal sepsis was associated with an increased risk of early cognitive developmental delays [107, 136], cerebral palsy [107, 123, 132, 135], general motor function delays [107], and autism spectrum disorders [114]. Additionally, infants who experienced neonatal sepsis were found to have a better IQ score in one of the two studies (the larger study) investigated the relationship between IQ and sepsis [138].

Retinopathy of prematurity (ROP)

Children affected by ROP are at a higher risk of experiencing blindness [141], NDI [86, 89, 102, 119, 129-132, 142], delayed early cognitive development [127, 136, 137, 142-144] and general language function [127, 136], reduced working memory/executive function [137], increased developmental coordination disorders [109], delays in general motor function [127, 142, 143], and gross motor function delay [117, 137, 144].

Necrotising enterocolitis (NEC)

NEC is associated with early cognitive delay [80, 127, 134, 136, 145] and shorter height [81, 146]. Additionally, NEC is associated with delays in general motor function [127, 134, 147, 148] and general behavioural difficulties [149]. Furthermore, children without NEC tend to exhibit better general language [127] scores compared to those affected by NEC.

Antenatal corticosteroids (ANS)

While antenatal corticosteroids have shown some effectiveness in reducing certain outcomes such as cerebral palsy [107, 150] and neurodevelopmental impairments [118], a closer examination of the overall articles included in these specific outcomes reveals that the reduction of these developmental outcomes is not statistically significant in included studies. A recent Cochrane review showed that antenatal corticosteroids probably lead to a reduction in developmental delay in childhood (RR 0.51, 95% CI 0.27 to 0.97) [151]. Antenatal corticosteroids demonstrated a protective effect against general motor function delay [107] and general behavioural difficulties [152].

Postnatal corticosteroids (PNS)

Post-natal corticosteroids are associated with an increased risk of growth failure [82, 125, 146], lower IQ/general cognitive ability [153], delayed early cognitive development [153], occurrence of CP [107, 108, 122, 153], poorer general motor [107, 108] and fine motor function [117], general behavioral difficulties [154], and positive screening for ASD [114].

Bronchopulmonary dysplasia (BPD)

BPD is associated with physical growth issues such as weight and height problems [80, 115, 125], a higher risk of respiratory tract infections [94, 95, 155, 156] and hospitalizations [157, 158], visual field deficit [159], NDI [86, 88, 89, 97, 102, 107, 130, 132], delays in early cognitive development [107, 136], lower cognitive ability [138, 160], compromised working memory/executive functions [160] and visuospatial skills [160], difficulties in functional feeding [134, 142] and general language function [136, 160], delays in receptive [160] and expressive [160] language, general motor function delays [107, 110, 117, 160], increase risk of autism spectrum disorders [114, 160], challenges in social relationship skills [160], and a reduced quality of life for children [92].

Neonatal surgery

Neonatal surgery was associated with an increase in NDI with major disability at both 3 and 8 years of age. Major disability was defined as moderate to severe cerebral palsy, blindness or deafness at 3 years with the additional of general intelligence Z score of less than -2 at the 8-year age timepoint. Neonatal surgery was also associated growth failure [81], NDIs [119, 126, 161], IQ scores less than 2 SD below the mean [161] and an increase in moderate to severe CP [161] at 8 years of age.

Neonatal seizures

Neonatal seizures were associated with bilateral blindness at 18-24 months of age [162], moderate and severe hearing impairment [162], NDI [162], and cognitive impairment [162].

Neonatal seizures were associated with overall CP in one of the included studies [142] of extremely low birth weight infants however were not associated in another large cohort studies including very preterm infants <29 weeks for either moderate or severe CP at 18-24 months of age [162]. Neonatal seizures were associated with mild motor impairments at 18-22 months of age as measure by the Bayley-2 Scale of Toddler Development [142].

Socioeconomic status

Among children born very preterm lower socioeconomic status increased the risk of asthma [163], NDIs [88, 101, 102, 107, 120, 132, 133, 140], early cognitive impairment or delay [107, 136, 164], functional feeding difficulties [134, 142], DCD [109], adaptive behaviours [113, 140, 154, 165, 166], poorer child quality of life [92, 167] and barriers to accessing follow-up services [93].

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.

Access to breastmilk in the neonatal/infant period

Studies were included for this component of the review if they reported outcomes of children who had access to breastmilk by any modality versus no access to breastmilk. The findings of the review suggest that no access to breastmilk resulted in an increased risk of early cognitive impairment [168, 169] and ADHD in EP (GA <26 w)[91, 169].

Adverse childhood experiences

Studies were included for this component of the review if they reported outcomes of children who experienced adverse childhood experiences compared with those who did not experience adverse childhood experiences in the first two years of life. Adverse childhood experiences were defined as neglect, abuse and child protective services involvement.

This review focused on investigating the impact of adverse childhood experiences on early cognitive development and general language function. The analysis included two eligible studies that examined the relationship between adverse childhood experience and outcomes of interest. The findings revealed that children who have experienced adverse childhood experiences have lower early cognitive [136] and general language scores [136] compared to those with no adverse childhood experience. However, it is important to note that the certainty of evidence for all included outcomes was determined to be very low when assessed using the GRADE approach indicating a high degree of uncertainty in the findings.

Geographical remoteness

The findings of the review indicated a significant association between geographical remoteness and not accessing high-risk follow-up services [93].

Culturally and linguistically diverse background

Children from CALD backgrounds form a heterogeneous group, and it is difficult to generalise findings to a specific subgroup. The findings of the review revealed that children from CALD backgrounds face significant risks in several areas. Specifically, children from CALD families exhibited a higher likelihood of experiencing low weight gain and smaller head circumference [82]. It is important that growth parameters need to be interpreted in the context of culturally appropriate growth charts and against mid-parental height. Additionally, children from CALD families were found to have a higher rates of

respiratory tract infections [95], early cognitive [107, 136] and language delays [90, 152], general behavioural difficulties [113, 154], and anxiety and internalizing behaviours [170].

2.4 Evidence to Recommendation Statement

Although children born VP have higher risk of growth, health and development problems, many do well. Knowledge of risk and resilience factors may help refine the program of follow-up care for each individual child born VP.

After reviewing the body of evidence, the GDG concluded that children born VP may present with multiple risk and resilience factors and that there are likely interactions between these factors. As such, stratifying access to follow-up care and/or reducing the recommended follow-up time points based on individual risk/resilience factors was not thought to be appropriate. Instead, the group acknowledged that information gained from follow-up visits at younger ages would provide more insight into the follow-up requirements at older ages, specifically alternative modes to in-person reviews and assessments (e.g., telehealth, screening questionnaires) for children identified as having lower risk for growth, health and developmental difficulties.

2.5 Recommendations

Consensus-based Recommendation 2

Structured, preterm-specific follow-up care should be offered to all children born very preterm and their caregivers, regardless of presence of risk and/or resilience factors.

Clinical Practice Points

Structured, preterm-specific post-discharge follow-up care

- 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 a hybrid (e.g., telehealth contacts facilitated with a local healthcare professional) based on families' preferences, clinical needs, and other relevant factors.

Future research priorities

The Guideline Development Group (GDG) noted that there is a lack of high-quality evidence investigating the impact of structured, preterm specific follow-up programs. Understanding impact, resources required, including appropriately skilled staff and cost-effectiveness of structured, preterm specific follow-up programs will require significant future research using a structured approach. Future research about risk and resilience factors that assesses their suitability for health, community and disability care decision making would add value, including those specific to an Aboriginal and Torres Strait Islander peoples. A partnership with people with lived experience to set research priorities for care for children and families who are born very preterm is necessary to ensure best use of research efforts and funding.

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Appendices

Appendix 1. Glossary

Term	Definition

Adverse childhood experience	Experiencing adversity during childhood that includes physical, emotional, or sexual abuse, neglect, household dysfunction and witnessing violence.
Antenatal corticosteroids	The administration of corticosteroids during pregnancy to promote lung maturity.
Attention deficit hyperactivity disorders	A group of disorders characterised by difficulties with attention and/or hyperactivity and impulsivity which are incongruent with a person's age and interfere with activities including a person's family life or participation in their community [171].
Autism spectrum disorders	A group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction, and by repetitive patterns of behaviour and restricted interests [172].
Brain injury	In this guideline brain injury is defined as having major (i.e., Grade 3 or 4) intraventricular haemorrhage and/or periventricular leukomalacia. An intraventricular haemorrhage occurs when there is bleeding inside or around the ventricles in the brain whereas periventricular leukomalacia occurs when there is damage to the white matter around the fluid-filled ventricles of the brain.
Bronchopulmonary dysplasia	A breathing disorder characterised by supplemental oxygen or respiratory support requirement at 36 weeks' postmenstrual age.
Cerebral palsy	A disorder of development of movement and posture, causing activity limitation, due to non-progressive disturbances occurring in the developing fetal or infant brain.
Cognition functions	Refers to cognitive development, general cognition (i.e. IQ), and specific cognitive skills such as attention, working memory, executive function and visuospatial skills.
Communication	Communication includes speech, language, voice and fluency skills.
Corrected age	Corrected age or adjusted age is a baby's age from birth (chronological age) minus the number of weeks or months early they were born. i.e., a 1 year old born 3 months early would have a corrected age of 9 months.
Developmental coordination disorder	A neurodevelopmental condition affecting a person's ability to learn and execute motor skills. It can make it difficult to perform common, everyday tasks such as doing up buttons, writing, catching, riding a bike or driving [173].
Feeding	Feeding is the act of eating or of taking or being given nourishment.
Geographical remoteness	Defined as having a significant distance and isolation from major urban or health service delivery centre.
Gestational age	Time elapsed since the first day of the last menstrual period until the baby born.
GRADE	GRADE (Grading of Recommendations, Assessment, Development and Evaluation) is used to rate the certainty or quality of a body of

	evidence. Each outcome area is given a rating from high to very low.
Language	Language is the comprehension and production of words, sentences, and texts for communication. This includes vocabulary (e.g., the store of words that an individual understands and uses), grammar/syntax (e.g., the way words are combined into phrases and sentences to form meaning), discourse (e.g., written language and text-level), social communication (e.g., skills needed to manage a conversation successfully, such as turn-taking, staying on topic, inferencing, ambiguity, jokes and metaphors) and literacy (e.g., reading, spelling and writing). Language can occur in many modalities, such as spoken, written and alternative augmentative domains (e.g., sign language, communication devices).
Necrotising enterocolitis	A disease of the intestinal tract, that typically affects preterm children, in which the tissue lining the intestine becomes inflamed and can die.
Neonatal sepsis	A generalised infection in newborn infants.
Neurodevelopmental impairment	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.
Postnatal corticosteroids	The administration of corticosteroids during postnatal period. Typically used to treat breathing problems.
Retinopathy of prematurity	An eye disorder that affects preterm infants, characterised by abnormal growth of blood vessels in the retina.
Sensory dysfunctions	In this guideline it refers to any impairment in relation to vision and hearing.
Small for gestational age	A birth weight that is characterised as more than two standard deviations below the mean or less than the 10th percentile for gestational age.
Quality of life	Quality of life refers to an individual's ability to participate based on functional outcomes. Quality of life is often considered alongside quantity (or duration) of life.
Speech	Speech is the production of speech sounds in words. It involves both articulation/motor speech production and linguistic skills (e.g., sounds, intonation, stress, prosody).
Very preterm	The term used to describe babies born alive <32 week's gestation.

Appendix 2. Abbreviations

Acronym	Expansion
ADHD	Attention deficit and hyperactivity disorder
AIMS	Alberta Infant Motor Scale
ASQ	Ages and Stages Questionnaire
AGREE II	Appraisal of Guidelines for Research and Evaluation II
BASC	Behavior Assessment System for Children
BITSEA	Brief Infant-Toddler Social and Emotional Assessment
BMI	Body Mass Index
BOT	Bruininks-Oseretsky Test of Motor Proficiency
BPFAS	Behavioural Pedatrics Feeding Assessment Scale
BSID	Bayley Scales of Infant and Toddler Development
BW	Birth Weight
CA	Corrected Age
CBCL	Child Behaviour Checklist
CELF	Clinical Evaluation of Language/Communication Fundamentals
ChOMPS	Child Oral and Motor Proficiency Scale
CI	Confidence Interval
CNFUN	Canadian Neonatal Follow-Up Network
CP	Cerebral Palsy
DAS	Differential Ability Scales
DBP	Diastolic Blood Pressure
DCD	Developmental Coordination Disorder
DQ	Developmental Quotient
ELBW	Extremely Low Birth Weight
ELGAN Cohort	Extremely Low Gestational Age Newborns cohort
EP	Extremely Preterm
EPICure cohort	EPIdemiological Study of Cerebral Palsy in Twins and Singletons Born at Less Than 28 Weeks of Gestational Age cohort
EXPRESS	Extremely Preterm Infants in Sweden Study
GA	Gestational Age
GDS	Gesell Developmental Schedules
GMA	General Movements Assessment

GMDS-GQ	Griffiths Mental Development Scale General Quotient
GMDS	Griffiths Mental Development Scale
GMFCS	Gross Motor Function Classification System
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
HC	Head Circumference
HINE	Hammersmith Infant Neurological Exam
ITSEA	Infant Toddler Social and Emotional Assessment
JBI	Joanna Briggs Institute
K-ABC	Kaufman Assessment Battery for Children
LBW	Low Birth Weight
LOVIS	LOngitudinal study of VISuomotor capacity in very preterm infants
MABC	Movement Assessment Battery for Children
M-CHAT	Modified Checklist for Autism in Toddlers
MDI	Mental Development Index
MDT	Multidisciplinary Team
NDI	Neurodevelopmental Impairment
NEPSY	Developmental NEuroPSYchological Assessment
NHMRC	National Health and Medical Research Council
NICHD	National Institute of Child Health and Human Development
NICUS	National Intensive Care Units
NR	Not Reported
NSMDA	Neurological, Sensory, Motor, Developmental Assessment
OR	Odds Ratio
PARCA-R	Parent report of Children's Abilities - Revised
PDI	Psychomotor Development Index
PICOT	Population, Intervention, Comparison, Outcome, Time
PLS	Preschool Language/Communication Scales
ROP	Retinopathy of Prematurity
RR	Relative Risk
SACS	Social Attention and Communication Surveillance tool
SBP	Systolic Blood Pressure
SD	Standard Deviation
SDQ	Strengths and Difficulties Questionnaire

SE	Standard Error
SGA	Small for Gestational Age
VICS	Victorian Infant Collaborative Study
VLBW	Very Low Birth Weight
VP	Very Preterm
WASI	Wechsler Abbreviated Scale of Intelligence
WISC	Wechsler Intelligence Scales for Children
WPPSI	Wechsler Preschool and Primary Scales of Intelligence

Appendix 3. Conflict of Interest Process

This policy is guided by the National Health & Medical Research Council (NHMRC) Standards and Guidelines for Guidelines. It applies to all members of the GDG and SC.

Definition of conflicts of interest

Conflicts of interest may occur in relation to financial, organisational, or other interests that might influence or appear to influence the independent performance of the responsibilities in developing this Guideline.

Financial interests include potential benefits arising as well as losses that may be incurred. Organisational interests can occur if group members serve as representatives of organisations with an interest in the guideline recommendations. Having a conflict of interest does not in itself imply unethical or improper behaviour. However, in order to ensure this Guideline is as free from bias as possible, all conflicts of interest must be identified, reviewed, and, where necessary, addressed by a clear management plan (section 4).

"Conflicts of interest can bias guideline recommendations to disproportionately favour new, expensive and less effective treatments and products. This is often to the detriment of both the public and the health systems on which they depend (Williams, Kevat et al. 2011). They can also promote over-diagnosis, over-treatment and lead to the medicalisation of normal human states and behaviours (Moynihan, Cooke et al. 2013)

It is inevitable that most people involved in guideline development will have an interest or stake in the process—this is typically why they were selected to participate in the first place. A conflict of interest arises when there is a risk that their professional judgment or actions regarding a primary interest (i.e., the guideline) will be unduly influenced by a secondary interest (such as financial gain) (Institute of Medicine 2009)."

NHMRC. Guidelines for Guidelines: Identifying and managing conflicts of interest. *https://www.nhmrc.gov.au/guidelinesforguidelines/plan/identifying-and-managing-conflicts-interest*. Last published 22/11/2018.

Examples of conflicts of interest:

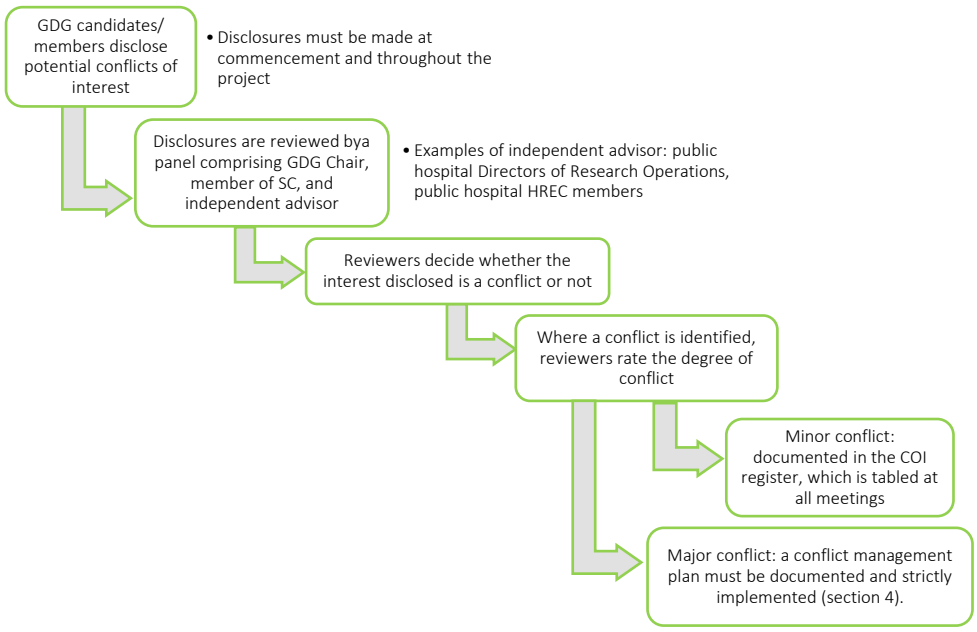
Financial conflicts of interest may include:	• fees paid for service to a company (e.g., consultancy payments, speaking fees, panel memberships). This includes for-profit and some not-for-profit organisations (e.g., Philip Morris Foundation for a Smoke-Free World). • indirect payments (e.g., funding of travel, accommodation, professional development, hospitality) • company stock • royalties • directorships • support for a researcher's clinical or research infrastructure (e.g., funding of data managers, scientists, equipment and clinical staff) • personal relationships with those who may have the above interests.

Organisational conflicts of interest may arise when:	• group members represent, or have roles in, organisations with financial links or affiliations with industry groups which stand to benefit from or be affected by guideline recommendations • group members represent, or have roles in, organisations which advocate known industrial or policy positions • group members have personal relationships with those who may have the above interests.

Taken from: NHMRC. Guidelines for Guidelines: Identifying and managing conflicts of interest. https://www.nhmrc.gov.au/guidelinesforguidelines/plan/identifying-and-managing-conflicts-interest. Last published 22/11/2018.

Process for Reviewing and managing conflicts of interest

The following process will be followed for identifying, reviewing, and managing potential conflicts of interest.



Management strategies for conflicts of interest

A management plan will be documented for each major conflict of interest. Depending on the nature of the conflicts disclosed, the following strategies may be used to manage conflicts of interest:

• a conflicted member being present but not taking part in any discussions or decision making related to the specific area or issue
• a conflicted member recusing themselves from a meeting when a decision or recommendation is made related to the conflict of interest
• excluding a conflicted member from involvement in the writing or approval of recommendations associated with the conflict
• removing a conflicted member from the guideline development group for failure to disclose major conflicts of interest
• a conflicted member eliminating potential conflicts of interest during the duration of guideline development (such as leave of absence from board positions)
• disallowing input from sponsoring organisations in guideline development
• ensuring that any decision to exclude members from discussion and decision making is made in full consultation with all members of the group and/or the independent assessors of the interests (such as a conflict of interest advisor or legal team) • *(Taken from: NHMRC. Guidelines for Guidelines: Identifying and managing conflicts of interest. https://www.nhmrc.gov.au/guidelinesforguidelines/plan/identifying-and-managing-conflicts-interest. Last published 22/11/2018)*

Consequences for failure to disclose relevant interests

In the event that a member does not disclose a relevant interest, the Chair of the GDG or Chair of the Steering Committee may terminate the individual's membership of the GDG or SC.

Appendix 4. Conflict of Interest Management

Guideline Development Group

Name	Interests disclosed	Management plan (if required)
Megan Bater	*Payment for lectures or educational tools/conducting training or test development:* I have a business name registered which I plan to launch post completion of my PhD in 2023. It will include teaching parents and assessing the development of children (including those born VP). I do not derive any income from this yet and won't until 18 months – 2 years from now. *Update:* 26/01/2024 *Employment:* Resigned from position as consultant RN, Neonatal Growth and Development Programme on 29/12/2023. Remains a PhD candidate at the University of Adelaide. Plans to move into private practice conducting Bayley-4 assessments and Newborn Behavioural Observations (NBO) in February 2024.	Continued disclosure. Update disclosure: no conflict; continued disclosure.
Amber Bates	*Memberships:* I hold a number of positions with other organisations as a Consumer Representative providing lived experience input as a parent of a child born very preterm. These organisations include Tiny Sparks WA, Telethon Kids Institute, Child & Adolescent Health Service (PCH), Woman and Infants Research Foundation, Ability WA, Woman and Newborn Health Service. For some of these positions I receive an honorarium for my contribution. *Other:* I am a named Associate Investigator on a number of research projects with yet to be published outcomes. *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	N/A Updated disclosure: no conflict; continued disclosure.
Siew-Lian Crossley	*Memberships:* I am coordinating a working group of neonatal speech pathologists in Neonatal Care across Australia/New Zealand. The focus of the group is on working with Speech Pathology Australia, our professional body to look at development of practice guidelines, competencies	Continued disclosure. Updated disclosure: no

	and training needs for speech pathologists in neonatal care. This is a newly established group and will be meeting quarterly, looking at developing this area of the speech pathology profession. *Employment:* I have a business "Northside Nurture" registered in my name. I plan to offer private lactation and speech pathology services once my youngest child is in primary school. Although the business is registered, it is not yet active and I do not plan to take on any private clients until April 2023 at least. *Update:* *Employment: 17/07/23* lactation practice has been closed down and practice dissolved. Commenced employment in a private feeding clinic called 'tiny bites'. Currently employed as a SP in feeding clinic which is run jointly with a dietitian from Offspring Health in Hawthorn. The clinic accepts self/medical referrals for infants and preschool children with functional feeding difficulties and communication impairments. The clinic runs fortnightly and services private, Medicare and NDIS patients. The clinic started in June 2023 and the role is currently for 12 months.	conflict; continued disclosure.
Cathryn Crowle	*Board Memberships:* Member of NIDCAP Board of Directors (non-financial) *Payment for lectures or educational tools:* Occasionally e.g., if invited to speak at a course or workshop. *Payment for conducting training or test development:* Not routinely, but possible as HINE trainer *Memberships:* Member of PSANZ & AusACPDM	Interests (particularly HINE trainer status) to be considered during allocation to evidence review and recommendation subcommittees
Amanda Dyson	*Memberships:* PSANZ long-term outcomes subcommittee; NICUS/ANZNN follow-up groups (both unpaid)	N/A
Madeleine Francis	*Memberships:* Founder of NICU Cheer a non-profit organisation that supports families in all of Melbourne's five NICUs at Mercy Hospital for Women, Royal Children's, Royal Women's, Monash Children's and Joan Kirner Women and Children's Hospitals. *Other:* Maddie also holds the position of NICU Ambassador for the Mercy Health Foundation which involves supporting and promoting their fundraising efforts and public speaking at events and has been invited by Mercy and RCH to speak to their NICU staff in CPD sessions about the lived NICU experience from the parent's perspective start date imminent but TBD.	N/A Updated disclosure: minor conflict, continued disclosure but no management plan required.

	Update: 30/10/2022 *Employment:* Olga Tennison Autism Research Centre in a newly created role as Training Coordinator for the SACS (Social Attention & Communication Screen) Tool. Position Start Date: 20th November 2023	
Joanne George	*Employment:* Employed by Queensland Health at Queensland Children's Hospital *Payment for lectures or educational tools:* Lectures to undergraduate physiotherapy students at Griffith University occasionally – paid to me. *Payment for conducting training or test development:* Payment for HINE training that I provide in the future, will be paid to Physiotherapy Department at Queensland Children's Hospital to reimburse my time and travel costs. *Other:* I lead a Steering committee developing recommendations for QLD state-wide follow-up of infants at risk of adverse neurodevelopmental outcomes. This work includes children born very preterm. I lead this work within my role at QH. No payment will be received personally or to my organisation for the development of these recommendations. *Update:* On 26/05/22 it was decided that QLD state-wide follow-up of infants at risk of adverse neurodevelopmental outcomes project would be put on hold until after the Preterm Follow-up Guideline is published.	Interests (particularly HINE trainer status) to be considered during allocation to evidence review and recommendation subcommittees
Traci-Anne Goyen	*Other:* NICUS member (non-financial)	N/A
Elizabeth Hurrion	*Other:* I am on the Steering Committee for the development of a similar Queensland-wide Guideline for the follow-up of high-risk infants (including preterm born infants), however myself and my institution do not receive any revenue from this role.	N/A
Leigh Hutchinson	None disclosed	N/A
Michelle Jackman	None disclosed	N/A
Elisha Josev	*Membership:* Member of PSANZ long-term outcomes subcommittee, PSANZ Academy, Australian Paediatric Neuropsychology Research Network. *Employment*: Employed by Mercy Hospital for Women (Victoria) as paediatric clinical neuropsychologist in a neurodevelopmental follow-up clinic where I regularly assess children born preterm. Also employed by Murdoch	N/A

	Children's Research Institute as a researcher in field of paediatric chronic illness.	
Amy Keir	None disclosed	N/A
Daniel Leach-McGill	None disclosed	N/A
Helen Lees	None disclosed	N/A
Felicity Lenck	*Employment:* Teacher with Department of Education	N/A
Christopher McKinlay	None disclosed	N/A
Angela Morgan	*Consultancy:* MCRI cost centre paid for my consultancy work with Deloitte in evaluating the speech pathologists in schools program for the Department of Education Victoria *Employment:* MCRI and The University of Melbourne *Payment for lectures or educational tools:* Speech pathology lectures to The University of Melbourne where I am employed	N/A
Bridget O'Connor	*Employment:* Kids Plus Foundation Baby Smart program using standardised assessment tools as part of routine follow-up program. *Payment for lectures or educational tools:* Flights and accommodation paid by Aust Physiotherapy Association for invited lecture at National conference in March 2022 [conference cancelled due to COVID] *Payment for manuscript preparation:* Paid for research time linked to this activity: Research output from ENVISAGE-Families research project. *Update:* Employment relationship ceased August 2022; some ongoing involvement with Kids Plus Foundation in their role as a consortium member of this recent federally funded grant (6.9 million) to roll out ENVISAGE - Families nationally. "The Australian Catholic University (ACU) Consortium, including key partner, the University of Melbourne, will deliver a peer support program that empowers, supports and connects caregivers early in their experience of raising a child with disability or developmental concerns. The consortium includes research, health and community services."	Interests (particularly employment status) to be considered during allocation to evidence review and recommendation subcommittees Updated disclosure reviewed by Chair, undergoing review by external panel
Colleen Oliver	*Payment for lectures or educational tools:* Payment for presentation on 'Post- discharge Nutrition in Preterm Infants' https://educationinnutrition.com.au/	N/A
Kelly Paterson	*Employment:* Role involved in development of local (RDH) and potentially regional (NT) guidelines for developmental care of at-risk infants and children	N/A

Tamara Porter	None disclosed	N/A
Angela Rajaratnam	*Employment:* I see very preterm children as part of my work.	N/A
Gehan Roberts	None disclosed *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	Updated disclosure: no conflict; continued disclosure.
Mary Sharp	*Employment:* Employed by Child and Adolescent Health Services	N/A
Javeed Travadi	None disclosed	N/A
Katrina Williams	None disclosed	N/A

Steering Committee

Name	Interests disclosed	Management plan (if required)
Peter Anderson	*Payment for conducting training or test development:* 1. Consultancy on development of the Bayley-4; 2. Reimbursed for expenses associated with collecting Australian normative data for the new Bayley-4; 3. Consultancy relating to the Brigance Inventory of Early Development *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	Interests (particularly involvement in Bayley Scales development) to be considered during allocation to evidence review and recommendation subcommittees Updated disclosure: no conflict; continued disclosure.
Alice Burnett	*Payment for lectures or educational tools/ conducting training or test development:* Invited lectures and workshops for graduate students (e.g., at the University of Melbourne, Swinburne University, La Trobe University) about health and developmental outcomes of prematurity, neuropsychological assessment, and related topics (0-3 times per year). *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	N/A Updated disclosure: no conflict; continued disclosure.
Jeanie Cheong	*Memberships:* Professional neonatal societies PSANZ, SPR (USA) *Consultancy:* Paid an honorarium by Elsevier for reviewing a proposal for a book on the Bayley-4 titled "Bayley-4: Clinical Use and interpretation" in regard to the merits as to whether it should be published. There is no ongoing arrangement and no further planned consultancy for the Bayley 4. *Employment:* RWH and MCRI	N/A Updated disclosure: no conflict; continued disclosure.

	Expert testimony: Have been asked to provide medical opinion on neonatal medicolegal cases *Payment for lectures or educational tools:* Guest lectures at UoM, Medical student tutorials at UoM, invited speaker (travel paid, some with honorarium): 2021 – Hot Topics in Neonatology USA; 2019 – Council of International Neonatal Nurses NZ, Congress of Global Children Healthcare Alliance China, KL International Neonatal Conference Malaysia; 2018 – IPOKRATES Belgium 2017 – Neonatal US workshop Singapore, KL International Neonatal Conference Malaysia *Payment for manuscript preparation:* Reviews for Seminars of Fetal and Neonatal Medicine (2017, 2019, 2020), Guest editor roles in Seminars of Fetal and Neonatal Medicine (2019) and Seminars of Perinatology (2021) *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	
Rod Hunt	None disclosed *Update:* *Other:* Investigator on publicly funded research grant (Australian Government; Medical Research Future Fund grant 2018596): "Targeted surveillance of developmental delay and impairments for young children born very preterm". Project Summary: aims to reduce the burden associated with developmental delay in children born very preterm by developing a family-focused surveillance program. Funding commenced 2022, completion 2027.	N/A Updated disclosure: no conflict; continued disclosure.
Jamie Owen	*Employment:* Royal Flying Doctors Service Victoria Casual Program Support Officer.	N/A

Past Guideline Development Group Members

Name	Interests disclosed	Management plan (if required)
Natasha Crow	None disclosed	N/A
Ingrid Rieger	*Employment:* On LSL (RPA Syd)	N/A
Melissa Ross	*Employment:* NICU, Westmead Hospital *Payment for conducting training or test development:* Consultant & Trainer for Pearson Bayley Scales of Infant Dev-4th Ed. *Other:* contribute to Neonatal Intensive Care Unit Study (NICUS) Group	Interests (particularly Bayley trainer status) to be considered during allocation to evidence review and recommendation subcommittees
Kathryn Schembri	*Employment:* Member of working group to develop model of care for NICU inpatient and follow-up services for the NT, resulting in business case.	N/A
Tracey Stephens	None disclosed	N/A

Appendix 5. Search Strategy for Existing Evidence-Based Guidelines.

The following websites were searched for any relevant guidelines.

- National Guideline Clearinghouse
- National Health and Medical Research Council (NHMRC) (Australia) NHMRC Clinical Guideline Portal and Emergency Care Portal (Australia) The National Electronic Library for Health (UK)
- Guidelines International Network
- Therapeutic Guidelines (Australia)
- National Institute for Health and Clinical Excellence (England／Wales) Medical Journal of Australia Clinical Guidelines (Australia)
- Joanna Briggs Institute (Australia)
- Guidelines Advisory Committee (Canada)
- TRIP database (UK)
- Canadian Medical Association Clinical Guidelines (Canada) Australasian College of Emergency Medicine (ACEM) (Australia) Canadian Association of Emergency Physicians (CAEP) (Canada)
- Royal College of Emergency Medicine (UK)
- Eastern Association for the Surgery of Trauma (EAST) (United States) Society of Critical Care Medicine (SCCM) (United States)
- Department of Veterans Affairs (Australia)
- International Council of Nurses
- Nursing Best Practice Guidelines (Canada)

NICE: final search update conducted 20/10/2016

Data Sources:

- Electronic health databases
- MEDLINE
- EMBASE
- The Cochrane Library
- PsychINFO

Internet search engines:

- Google
- Google Scholar

Appendix 6. Clinical Practice Point: Predictive and Prognostic Tools

The Guideline Development Group (GDG) discussed the need for guidance 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. 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.

Table 11 - Predictive and prognostic tools

Developmental outcome domain	D/C to 3mo CA	6-12mo CA	18mo CA	2-2.5y CA	4-5y CA
Multiple domains:					
• **Bayley Scales of Infant and Toddler Development- 4th Edition** [a] [174]		X	X	**X**	
• Griffiths Scales of Child Development 3rd Edition [c] [175]			X	X	X
• **Ages and Stages Questionnaire** [f] [176]	X	X	X	**X**	X
• Mullen Scales of Early Learning [177]	X	X	X	X	X
• Parent report of Children's Abilities -Revised (PARCA-R) [f] [178]				X	
Cognition					
• **Wechsler Preschool and Primary Scales of Intelligence-IV (WPPSI-IV)** [179]				X	**X**
• NEPSY-II [180]					X
• Differential Ability Scales 2nd Edition (DAS-II) [a] [181]					X
• Kaufman Assessment Battery for Children 2nd Edition (KABC-2) [182]					X
• Beery-Buktenica Developmental Test of Visual-Motor Integration [183]					X
Feeding					
• Feeding assessments [184]	X	X	X	X	X
• Child Oral and Motor Proficiency Scale (ChOMPS) [185]		X	X	X	X
• Behavioural Pediatrics Feeding Assessment Scale (BPFAS) [186]		X [e]	X	X	X
Language/Communication					
• Preschool Language/Communication Scales-5th Edition (PLS-5) [187]	X	X	X	X	X
• Clinical Evaluation of Language/Communication Fundamentals-5th Edition (CELF-5) [188]					X

Developmental outcome domain	D/C to 3mo CA	6-12mo CA	18mo CA	2-2.5y CA	4-5y CA
Motor					
• **General Movements (GM) Assessment [189] and GM Motor Optimality Score** [190][a]	**X**				
• Alberta Infant Motor Scale [191]	X	X	X		
• Peabody Developmental Motor Scale 2nd [192]	X	X			
• The Neurological, Sensory, Motor, Developmental Assessment (NSMDA) [a d] [193]	X	X	X	X	X
• **Hammersmith Infant Neurological Exam (HINE) [194] [b]**		**X**	X	X	
• Developmental Coordination Disorder Questionnaire (DCD-Q) [195] /Little DCD-Q [196]					X
• Bruininks Oseretsky Test of Motor Proficiency (BOT) [197]					X
• Movement ABC-2 [198]					X
Behaviour					
• **Infant-Toddler Social and Emotional Assessment (ITSEA)** [199]		X [e]	X	**X**	
• Modified Checklist for Autism in Toddlers-Revised with Follow-up (M-CHAT-R/F) [200]			X	X	
• Social Attention and Communication Surveillance (SACS) Approach [a] /ASDetect [f] [201]		X [e]	X	X	
• Behavior Assessment System for Children 3rd Edition-(BASC-3)[202] [a]				X	X
• Child Behavior Checklist (CBCL) [203]				X	X
• **Strength and Difficulties Questionnaire (SDQ)** [204] [f]				X	**X**

Measurement tools and timepoints presented in **bold** are recommended by the GDG. Footnotes: [a] Specialised training required, [b] Specialised training recommended, [c] Recommended use when >3.5 years and unable to do an IQ assessment, [d] NSMDA can be used from 1 month corrected age, [e] BPFAS, ITSEA and ASDetect from 12 months corrected age, [f] Parent questionnaire/tool.

<u>Physical Health (across all timepoints)</u>

Multiple domains

- Medical assessment/history

Growth & Nutrition

- Growth reference charts (WHO Child Growth Standards) [205]

Respiratory

- 10-item Predicting Asthma Risk in Children (PARC) questionnaire (can be used from 12 months CA) [206]

Quality of Life (across all timepoints)

- PedsQL-4 [207] (from 24 months CA)
- Infant and Toddler Quality of Life Questionnaire [208]

Parental wellbeing/mental health (across all timepoints)

- Hospital Anxiety and Depression Scale (HADS) [209]
- Generalised Anxiety Disorder Assessment (GAD-7) [210]
- Center for Epidemiologic Studies Depression scale (CES-D) [211]
- Depression, Anxiety and Stress Scale (DASS) [212]
- PTSD Checklist-Civilian version [213]