BANNFU
British Association for Neonatal
Neurodevelopmental Follow-Up

British Association of
Perinatal Medicine
Special Interest Group

August 2025

Developmental follow-up, surveillance, and support at the age of four years

A DRAFT BANNFU Best Practice Guide

British Association of Neonatal Neuordevelopmental Follow-Up

Contents

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About BANNFU

The British Association for Neonatal Neurodevelopmental Follow-up (BANNFU) is a Special Interest Group of the British Association of Perinatal Medicine (BAPM). BANNFU is a multidisciplinary group which exists to improve the long-term outcomes of all babies that have had neonatal care by disseminating best practice and improving care.

Our Vision

We are a multidisciplinary, national, multi-professional group who have come together to develop this best practice guide, supported by BANNFU (the British Association of Neonatal Neurodevelopmental Follow-Up). Our aim is to help clinical teams structure and deliver a service for developmental follow-up, and to facilitate appropriate intervention, at four years of age for at-risk children. With representation from education, early years, psychology, health and caregivers, our recommendations have been considered from each viewpoint. Our shared vision is to improve developmental follow-up and educational experiences for children whose early experiences put them at risk of additional learning needs, facilitating lifelong learning, participation and wellbeing.

Scope of document

The purpose of this best practice guide is to support clinicians in developing and delivering a four-year developmental follow-up service for children whose perinatal or neonatal experiences put them at high chance of developmental conditions or additional learning needs. Specific service arrangements will vary depending on local resources and existing services. We provide evidence and suggestions for minimum standards. We describe which children should be included in this service, what assessments may be beneficial, and how this can support schools to be ready for, and support, this cohort of children and their families.

The document is aimed primarily at professionals but will be freely available via the BANNFU website. This best practice guide should be incorporated into local and network guidelines to evaluate current practice and inform the development of new services.

Abbreviations

ABAS-3 – Adaptive Behaviour Assessment System 3rd Edition
ADHD – Attention-Deficit/Hyperactivity Disorder
ALN – Additional Learning Needs
ASQ-3 – Ages and Stages Questionnaires 3rd Edition
BANNFU – British Association of Neonatal Neurodevelopmental Follow-Up
BAS3 – British Ability Scales 3rd Edition
BOT-2 – Bruininks-Oseretsky Test of Motor Proficiency 2nd Edition
BRIEF-P – Behaviour Rating Inventory of Executive Function, Preschool Version
CBCL – Child Behavior Checklist
CCC-2 – Children's Communication Checklist-2
EHC – Education, Health and Care
GMFCS – Gross Motor Function Classification System
GP – General Practitioner
HIE – Hypoxic Ischaemic Encephalopathy
MACS – Manual Ability Classification System
Movement ABC-3 – Movement Assessment Battery for Children, 3rd Edition
NICE – National Institute for Health and Care Excellence
PLS-5 – Preschool Language Scale 5th Edition
PRISM – Premature Infants' Skills in Mathematics Study
SCQ – Social Communication Questionnaire
SDQ – Strengths and Difficulties Questionnaire
SEND – Special Educational Needs and Disabilities
SENIT – Special Educational Needs and Inclusion Team
SLT – Speech and Language Therapy
SOGS II – Schedule of Growing Skills II
VABS-3 – Vineland Adaptive Behaviour Scale 3rd Edition
VMI – Visual Motor Integration
WPPSI-IV UK – Wechsler Preschool and Primary Scales of Intelligence 4th UK Edition

Background

Perinatal care aims to improve both survival and long-term developmental outcomes for children who require neonatal care. Monitoring and supporting these children beyond their time in the neonatal unit is important for three main reasons:

1. To identify needs for additional support or early intervention for individual children and their families in a timely manner.
2. To support data collection for national surveillance, benchmarking, and planning service provision.
3. To allow research questions about neonatal care to be answered by investigating developmental outcomes associated with the interventions provided, and the long-term effects of complications during the perinatal period.

Preterm infants have increased chances of developmental challenges, including cerebral palsy, cognitive impairment, visual/hearing impairment, attention deficit/hyperactivity disorder, autism, and poor educational attainment[1–3]. Neonatal encephalopathy is also associated with long-term poor cognitive and behavioural development, and poor educational attainment[4–6].

There is no "gold standard" for developmental follow-up. Across Europe there is variation in follow-up, but surveillance until at least four years of age is established in several countries[7]. Within the UK, National Institute for Health and Care Excellence (NICE) guidance recommends follow-up to four years of age to enable an assessment just prior to school entry for infants born below 28 weeks' gestation[8,9], with this one of the four NICE Quality Statements[10]. However, presently not all UK neonatal units have dedicated local developmental services[11]. Currently 88% of neonatal units offer developmental follow-up to two years of age, and only 6.8% to four years of age[12]. Four-year follow-up was highlighted as an area requiring urgent improvement by the House of Lords Preterm Birth Committee[13] . Improving follow-up is a key concern for the parents of preterm infants, including extending the duration of follow-up and a focus on outcomes that can inform and support the transition to education[14].

The economic cost of preterm birth beyond the immediate neonatal period is large, including within health and social care services, special educational needs provision, costs to families, for example for informal care, and costs to society, for example through work absence[15]. These costs increase with earlier birth gestation, medical complexity, and sociodemographic factors[16]. Similar wide-ranging economic costs are seen after neonatal encephalopathy[17]. Developmental follow-up prior to school could help to reduce these costs through earlier detection and intervention[18]. The aim of this document is to inform and support clinical teams who are establishing their own service.

Summary recommendations

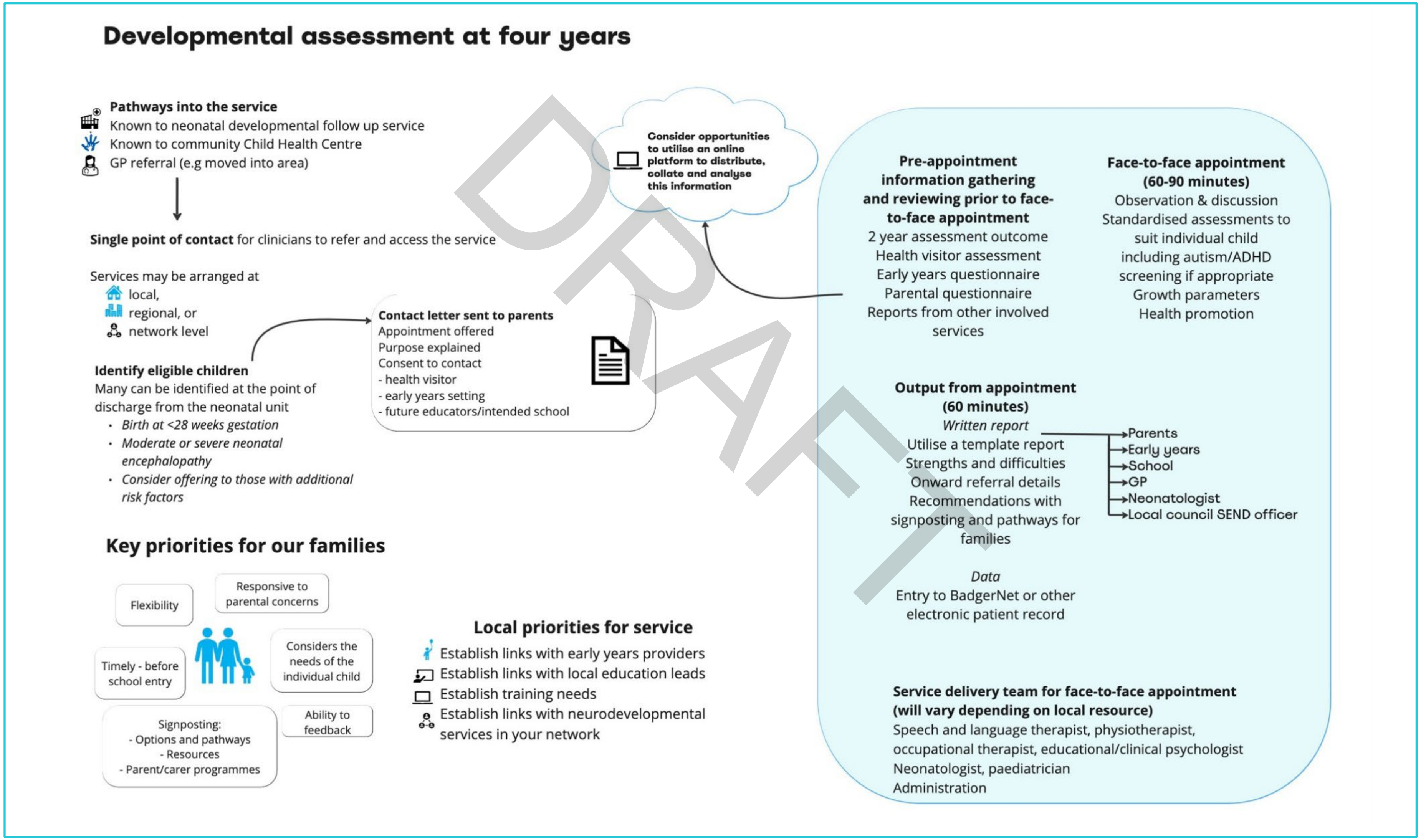
1. Follow-up at four years of age should include as a minimum those born before 28 weeks' gestation, and infants with moderate to severe neonatal encephalopathy, but other infants with risk factors for developmental problems or disorders should be strongly considered.

2. Follow-up should include assessment of the following domains: physical development and growth, cognitive development, emotional and behavioural development, sensory needs, and social skills and relationships. This should be through a combination of in-person direct assessment, and caregiver and teacher questionnaires.

3. A summary report should be shared with the caregivers, GP, health visitor, neonatal consultant, other healthcare practitioners involved in the child's care, and once consent is obtained, with the child's early years practitioner, current or future school, and local council SEND officer and/or safeguarding services if appropriate. This should describe the child's strengths and needs to support transition into and throughout education.

4. Neonatal networks should oversee and promote coordination of follow up at four years of age, and collation of information for monitoring the service.

Figure 1: Ecosystem summary of the developmental follow-up, surveillance, and support at the age of four years.
ADHD – Attention-Deficit/Hyperactivity Disorder, GP – general practitioner, SEND - Special Educational Needs and Disabilities.



Developmental assessment at four years

Pathways into the service
Known to neonatal developmental follow up service
Known to community Child Health Centre
GP referral (e.g moved into area)

Single point of contact for clinicians to refer and access the service

Services may be arranged at
local,
regional, or
network level

Identify eligible children
Many can be identified at the point of discharge from the neonatal unit
- *Birth at <28 weeks gestation*
- *Moderate or severe neonatal encephalopathy*
- *Consider offering to those with additional risk factors*

Contact letter sent to parents
Appointment offered
Purpose explained
Consent to contact
- health visitor
- early years setting
- future educators/intended school

Consider opportunities to utilise an online platform to distribute, collate and analyse this information

Pre-appointment information gathering and reviewing prior to face-to-face appointment
2 year assessment outcome
Health visitor assessment
Early years questionnaire
Parental questionnaire
Reports from other involved services

Face-to-face appointment (60-90 minutes)
Observation & discussion
Standardised assessments to suit individual child including autism/ADHD screening if appropriate
Growth parameters
Health promotion

Output from appointment (60 minutes)
Written report
Utilise a template report
Strengths and difficulties
Onward referral details
Recommendations with signposting and pathways for families

→Parents
→Early years
→School
→GP
→Neonatologist
→Local council SEND officer

Data
Entry to BadgerNet or other electronic patient record

Service delivery team for face-to-face appointment (will vary depending on local resource)
Speech and language therapist, physiotherapist, occupational therapist, educational/clinical psychologist
Neonatologist, paediatrician
Administration

Key priorities for our families

Flexibility
Responsive to parental concerns
Timely - before school entry
Considers the needs of the individual child
Signposting:
- Options and pathways
- Resources
- Parent/carer programmes

Ability to feedback

Local priorities for service

Establish links with early years providers
Establish links with local education leads
Establish training needs
Establish links with neurodevelopmental services in your network

Children qualifying for follow-up at four years of age

There are many factors that can increase the chance of developmental challenges or special educational needs and disabilities (SEND). Which children are considered as eligible for developmental follow-up at four years of age may differ depending on population-specific characteristics and local resources. As a minimum, follow-up should include preterm infants born before 28 weeks' gestation, and infants with moderate to severe neonatal encephalopathy (Box 1).

Box 1. Children requiring follow up at four years of age – minimum

Infants born before 28 weeks' gestation
Infants with moderate to severe neonatal encephalopathy

All those qualifying locally for two-year follow-up should, however, be strongly considered. NICE guidelines state those eligible for two-year follow-up include at least all babies born before 30 weeks' gestation, and those born between 30+0 and 36+6 weeks' gestation with at least one additional risk factor of grade 3/4 intraventricular haemorrhage, cystic periventricular leukomalacia, moderate to severe neonatal encephalopathy, bacterial meningitis, or herpes simplex encephalitis[8].

Other children who should be considered for four-year follow-up are those with an additional risk factor for adverse developmental outcomes as described in Box 2.

Planning which infants to follow up will require local services to identify the number of infants qualifying in their region. National data gives rates of 2 per 1000 live births for moderate to severe neonatal encephalopathy, and 5 per 1000 live births for babies born <28 weeks' gestation[19,20]. If follow-up is extended to preterm infants born <32 weeks' gestation[1,2], this increases to 10 per 1000 live births[19].

Box 2. Additional factors that increase risks of adverse long-term developmental outcomes

Small for gestational age[21]
Grade 3/4 intraventricular haemorrhage[22]
Post-haemorrhagic ventricular dilatation[23,24]
Cystic periventricular leukomalacia[25]
Sepsis[26,27]
Meningo-encephalitis[28]
Necrotising enterocolitis requiring surgery[29,30]
Bronchopulmonary dysplasia[31,32]
Retinopathy of prematurity requiring treatment[33,34]
Cardiac anomalies, particularly if requiring surgery[35,36]
Other major or multiple congenital abnormalities, particularly if requiring ECMO[37–39]
Extra-corporeal membrane oxygenation treatment[40]
Fetal alcohol spectrum disorder[41,42]
Kernicterus[43]
Social deprivation (e.g., using national Index of Multiple Deprivation from postcode[44–47])[48,49]

Identifying children for four-year follow-up

This will begin in the neonatal unit, with follow-up stages explained to families prior to discharge, and information given about the importance of follow-up. Gathering additional contact details (email addresses, mobile numbers) and permission to use them is helpful. There should be a clear pathway, ideally with a single point of contact or appointed local care coordinator between appointments, although this may not be possible when follow-up is being offered across teams (e.g., neonatal and community paediatrics). A generic email address and/or phone number could be established.

At the time of coordinating four-year appointments, the majority of children will have been identified at their two-year follow-up appointment, as they are likely to be a subgroup of these. However, local systems should be in place to identify children who were not invited or not brought to their two-year appointment. There should also be the ability for GPs and health visitors to refer children from the community who meet the specified criteria, for example if they have moved into the area.

There will be children within this cohort who are already under developmental follow-up by other teams by four years of age, for example neurology, neurodisability, or community child health services. Local pathways should be developed to ensure all children are identified and receive tailored additional advice and guidance as they enter school. There is no need for duplication, but if this is not provided by their other services children should be offered an appointment via their local neonatal developmental follow-up service. The purpose of this appointment should be explained to families.

Links should be established with these additional services (e.g., neurology, neurodisability, and community child health services) so that information can be gathered, with local pathways to ensure complete data collection within the neonatal follow-up system. If a child is referred to another service for developmental follow-up, there is an expectation that information from developmental assessments is fed back to the neonatal team and neonatal network, specifically from assessments carried out at two and four years of age. This data will be collated via Badgernet; a four-year developmental follow-up page is under development.

Performing the developmental review

Pre-appointment

At the time of opting into the service, consent from families should be obtained to contact the child's early years practitioner or teacher to gather information and share findings. Information will also be gathered from other health professionals such as their GP and health visitor, specialist and general paediatricians, and any other teams already involved with the child such as speech and language therapists (SLTs), physiotherapists, occupational therapists, psychologists, or dietetics. Discharge letters from their neonatal unit stay and correspondence from previous developmental assessments should be gathered. Information from other health professionals will need collating depending on local services and shared IT platforms. A virtual platform for hosting this information in one place would be beneficial.

Both the caregivers and the child's early years practitioner or teacher should be given questionnaires to complete in advance of the face-to-face appointment. Ideally these should be available online or on paper, with options of languages other than English. See Appendix 1 for details of assessment options.

Suggested minimum questionnaires for use at four years of age (see Appendix 1 for more details):

- Strengths and Difficulties Questionnaire (SDQ)[50] completed by the child's parent/caregiver.
- Ages and Stages Questionnaires (3rd Edition, ASQ-3)[51] completed by the child's parent/caregiver.

Suggested questionnaire for teacher:

- SDQ[50] completed by the child's teacher or early years practitioner.

Education practitioners should also share any other specific comments or concerns, or available reports. For some children, educational needs assessments may already be underway - these include Educational, Health and Care (EHC) needs assessments in England, Additional Support for Learning in Scotland, Plan of Arrangements in Northern Ireland, and Additional Learning Needs (ALN) assessment in Wales.

Safeguarding concerns should always be considered, and information should be gathered from social care teams if relevant. If children are not brought to the appointment, consider if this is a safeguarding concern.

Appointment

Appointments should be face-to-face. The appointment should initially be guided by any family concerns and questions, alongside information from the pre-appointment information gathering.

The key areas for assessment are physical development, cognitive development, emotional and behavioural development, and social skills and relationships. These can be assessed through history taking with the family and unstructured child assessment and play. History taking should include consideration of the social determinants of health, including adverse childhood experiences and poverty[52–54]. Consider if there are any psychological needs for the child or family. Psychological support after discharge from the neonatal unit should be available at any neonatal follow-up appointment[55] .

There are options for structured assessments depending on the training of those undertaking the assessment and the time available. These are summarised in Appendix 1 – those recommended by NICE[8] are highlighted. All developmental domains should be covered, through a combination of direct child assessment and caregiver/teacher questionnaires. Regardless of which of these are used, it is important to maintain flexibility within assessments to respond to family concerns and individual needs.

There are also a number of specific medical outcomes to explore and refer onward if required.

Biometric measurements should be taken and plotted, including height, weight, head circumference, and blood pressure. These will monitor for growth but also identify potential issues such as obesity and hypertension, that are more common in preterm infants in particular[56,57].

If cerebral palsy is present, the Gross Motor Function Classification System (GMFCS)[58] and Manual Ability Classification System (MACS)[59] scores should be recorded.

Vision and hearing screening may be conducted between 4 and 5 years of age as part of the national Healthy Child Programme, depending on local commissioned pathways[60]. Share details of local screening pathways with families. Refer for formal assessment if there are specific concerns, for example audiology screening if any speech and language concerns.

Sleep problems are common after preterm birth and neonatal encephalopathy[61–63]. Discussion may highlight simple interventions such as sleep hygiene, or the need for referral for more detailed assessment.

Feeding problems are also common in children born preterm or are at high risk of adverse developmental outcomes[64–66], including problems with chewing and swallowing, gastro-oesophageal reflux, and restricted diets. Concerns may require referral for assessment by therapists such as SLTs, occupational therapists, and dietitians. Oral and dental health can also be affected[64,67,68], so encourage dental hygiene, routine dental assessment, and refer to specialist services if required.

Health promotion

As a vulnerable group of children, this interaction with a health professional should be used to ensure routine health promotion is undertaken. This includes confirming vaccination status as per national immunisation schedules[69], advice about accident avoidance and safety, encouraging vitamin supplements alongside a health, balanced diet (vitamins A, C and D are recommended from six months to five years of age[70]) and advising physical activity (at least 180 minutes a day, including active and outdoor play[71]).

Post-appointment

A summary report (see Box 3) should be shared with the caregivers, GP, health visitor, neonatal consultant, other healthcare practitioners involved in the child's care, and once consent is obtained, with the child's early years practitioner, current or future school, and local council SEND officer and/or safeguarding services if appropriate. If consent wasn't obtained prior to the appointment for data sharing with the child's early years setting or school, this should be discussed at or following the appointment.

Box 3. The summary report after the appointment

Detail the child's strengths and needs.
Use terminology which is helpful for education providers to plan support if needed.
Be written in a style that is easily understood by families.
Detail any onward referrals and future appointments.
Include personalised advice to support the child's transition to school and to support instructional planning if needed.

Early contact between schools and caregivers enables best transition, with planning ideally starting as soon as primary school placement is confirmed, alongside nursery and/or preschool. This report should be used to facilitate this discussion.

The contents of this summary report should be helpful for the professional developing an educational needs assessment document (EHC in England, Additional Support for Learning in Scotland, Plan of Arrangements in Northern Ireland, ALN in Wales) if appropriate. There should be discussion with caregivers about local SEN provision, including within mainstream schools, special schools, and home-schooling. We recognise it can be challenging for healthcare professionals to stay informed about the range of support available within education. Discussions about educational pathways should include signposting to local educational authority contacts who can give fuller information about resources and options available to families. Share details of local schools with Prem Aware Award status (see Appendix 2). Also discuss the options available for delaying or deferring entry to primary school, according to the child's individual needs or circumstances.

Onward referrals will depend on the findings of the assessment, but could include speech and language therapy, physiotherapy, occupational therapy, dietitian, neurologist, ophthalmology, audiology, community nurses, child/adolescent mental health services, community child health services, psychology, or social services.

Signpost to national resources and groups for caregivers and schools (Appendix 2), and local resources. Teams should be aware of current eligibility for local and national financial support. This could be specialist funds, like Personal Health Budgets for children in England with NHS Continuing Care[72], or local food banks and charities.

Implementation and training

Implementation and coordination should be centralised across neonatal networks, who will oversee and promote service development and information collation. Neonatal networks will support and drive collaboration, to develop regional guidance for local teams to deliver services.

Funding for services will need to be established. A previous successful business case for a similar service is included (Appendices 1 and 2) but advocating for more support at a regional and national level is required. Four-year follow-up was highlighted as an area requiring urgent improvement by the House of Lords Preterm Birth Committee[13], which we hope will help facilitate this.

Teams should look to develop links with education services locally, both early years and primary schools. This should also aim to identify and include local home-schooling groups, which may be through local authorities.

Data sharing agreements and protocols between the various hospital trusts and agencies should be created.

Administrative support is required for identifying eligible children and coordinating the pre-appointment data collection. Information about the four-year developmental assessment should be shared with neonatal and paediatric teams, and regional health visitors and GPs to maximise referrals. There should be equity to support all children to attend follow-up, including those who are new to the area, or have not attended two-year follow-up. Translation and interpretation (verbal and written) services should be available for families where English is not their first language. Support should also be provided to allow visually- or hearing-impaired children and families to participate fully.

Team members and locations

This will vary depending on existing structures, but involvement of allied health professionals is critical for a comprehensive developmental follow-up service. Griffiths-III[80] and WPPSI-IV[87] require additional training, and the tools recommend administration by a clinical or educational psychologist. Four-year developmental follow-up may be embedded within neonatal services, within general paediatrics if there are staff members with a developmental interest, or within community paediatric services. Psychology teams should be involved in the development of services to ensure they are psychologically safe, and to provide ongoing support for children and families after discharge from the neonatal unit[55] .

Administration

Each appointment will take 60-90 minutes depending on the assessments included. There will be approximately 60 minutes of administrative time for each appointment, gathering the information from the different sources, scoring assessments, and writing reports. Electronic platforms for scoring and collating information should be considered as these are likely to reduce administration time.

A four-year developmental follow-up page is under development for within Badgernet, alongside relevant local digital platforms. This will allow developmental outcomes to be collated, reviewed, and analysed, to allow a greater understanding of the developmental outcomes of these children. The outcomes of the assessment should be inputted into Badgernet electronic records. This may need to be through passing information and reports to the child's neonatal service if the assessment is performed elsewhere. These data are recommended to become incorporated into the National Neonatal Audit Programme to monitor compliance and outcomes.

Included is an example of a previous successful business case for a similar service (Appendices 1 and 2). Please use local or regional business case templates, for example several are available from NHS England.

Research questions, quality assurance and audit

1. **What is the impact of four-year follow-up assessments on health and educational outcomes?**
   As part of the NICE guideline[8], routine education measures at Key Stage 2 should be gathered to allow educational outcomes at 11 years-of-age to be linked to neonatal information. The utility of the four-year follow-up programme should be established through the assessment of educational and health outcomes, through routinely collected data. This should include assessment of the predictive accuracy of the assessment tools used between services, to determine whether more uniform recommendations for assessment methods should be developed.

2. **Does enhanced developmental support and surveillance at four years of age benefit parents and carers of children born preterm?**
   Caregiver feedback should be used to assess the acceptability and utility of the four-year developmental follow-up service, to inform service development.

3. **Are all eligible infants assessed at four years?**
   This will be initially through local audit processes at neonatal network level. It is recommended to become incorporated into the National Neonatal Audit Programme. This should include outcome data as well as uptake.

Appendix 1. Structured assessments that may be used to assess the developmental domains of interest

Assessment	**Domain assessed**	**Summary**	**Logistics**	**Online link**
Adaptive Behaviour Assessment System, 3rd Edition (ABAS-3) – Infant and Preschool[73]	Adaptive/functional needs	0-5y. Caregiver/teacher questionnaire. Domains: conceptual, social, practical.	15-20 for caregivers/teachers. Online version available. Cost (paper): £724.80 starter kit, £144 for 25 caregiver forms, £144 for 25 teacher forms. Online scoring available.	ABAS-3
Ages and Stages Questionnaires, 3rd Edition (ASQ-3)[51]	Global	1-66m. Caregiver questionnaire. Domains: communication, gross motor, fine motor, problem solving, and personal-social. Screening. Languages: Arabic, Chinese, English, French, Spanish, Vietnamese. Recommended by NICE[8].	15min for caregivers, 3min for scoring. Online version available. Cost: $295 starter kit, $240 for 21 forms (approximately £235 and £190 respectively).	ASQ-3
Behaviour Rating Inventory of Executive Function, Preschool Version (BRIEF-P)[74]	Executive Function	2y-5y11m. Caregiver questionnaire. Scales: global executive composite, inhibitory self-control, flexibility, emergent metacognition. Languages: English, Spanish.	15min for caregivers, 15min for scoring. No online version currently. Cost: £279 starter kit, £110 for 25 forms.	BRIEF-P
British Ability Scales, 3rd Edition (BAS3) – Early Years[75]	Cognitive development	3-5y11m. Direct child assessment – screening. Scales: verbal ability, non-verbal reasoning ability, spatial ability. Languages: English, Spanish, Italian.	30-45min. In person. Recommended to be done by educational/clinical psychologist and/or professional with appropriate training. Cost: £1650 starter kit, £81.50 for 25 Early Years record booklets. Online scoring available.	BAS3
Bruininks-Oseretsky Test of Motor Proficiency, 2nd Edition (BOT-2, brief form)[76]	Motor	4-21y. Direct child assessment - screening. Fine motor, gross motor.	15-20min (long version 45-60min). In person. Cost: £337.20 starter kit, £38.40 for 25 forms.	BOT-2
Child Behavior Checklist (CBCL Preschool)[77]	Social/emotional development	1.5-5y. Caregiver questionnaire. Scales: emotionally reactive, anxious/depressed, somatic complaints, withdrawn, attention problems, aggressive behaviour. Languages: >90 languages available.	15-20min for caregivers. Online version available. Cost: $170 starter kit, $40 for 50 forms (approximately £135 and £32 respectively).	CBCL-preschool
Children's Communication Checklist-2 (CCC-2)[78]	Autism/social/communication	4-16y. Caregiver questionnaire. Screening. Scales: general communication composite, social interaction deviance composite.	5-15min for caregivers. Online version available. Cost: £214.77 starter kit, £64.80 for 25 forms.	CCC-2

Conners Early Childhood (EC)[79]	Attention/ behaviour/ Attention-Deficit/ Hyperactivity Disorder (ADHD)	2-6y. Caregiver/teacher questionnaire. Screening. Scales: adaptive skills, communication, motor skills, play, pre-academic/cognitive.	25min for caregivers/teacher. Online version available. Cost: £119 manual, £129 for 25 caregiver forms, £129 for 25 teacher forms.	Conners EC
Griffiths Scales of Child Development, 3rd Edition (Griffiths III)[80]	Global	0-5y11m. Direct child assessment. Domains: foundations of learning, language and communication, eye and hand coordination, personal-social-emotional, gross motor. Languages: English, Italian, Portuguese, Swedish, French, Brazilian.	60 min. In person. Recommended to be done by educational/clinical psychologist and/or professional with appropriate training. Cost: £1695 starter kit, £59.50 for 10 forms.	Griffiths III
Movement Assessment Battery for Children, 3rd Edition (Movement ABC-3)[81]	Motor	3-25y. Direct child assessment. Gross/fine motor coordination: manual dexterity, aiming and catching, balance and locomotion.	30-45min. Online version available. Cost: £1242.37 starter kit, £90 for 25 forms.	Movement ABC-3
Preschool Language Scale 5th Edition (PLS-5)[82]	Language	0-7y11m. Direct child assessment. Domains: preverbal skills, language content/structure, integrative language skills, emergent literacy.	45-60min. In person. Cost: £642.55 starter kit, £124.80 for 25 forms.	PLS-5
Schedule of Growing Skills II (SOGS II)[83]	Global	0-5y. Direct child assessment. Domains: locomotor, manipulative, visuals, hearing and language, speech and language, interactive social skills, self-care, cognitive.	20min. Cost: £304 starter kit, £178 for 50 forms	SOGS II
Social Communication Questionnaire (SCQ)[84]	Autism/social/ communication	4y+ (as long as mental age 2y+). Caregiver questionnaire. Screening. Languages: English, Danish, Dutch, Finnish, German, Hebrew, Hungarian, Icelandic, Italian, Japanese, Korean, Norwegian, Romanian, Russian, Spanish, Swedish.	5-10min for caregivers. Online version available. Cost: £229 starter kit, £74 for 20 forms.	SCQ
Strengths and Difficulties Questionnaire (SDQ)[50]	Social/ emotional development	2-17y. Caregiver/teacher questionnaires. Screening. Scales: emotional problems, conduct problems, hyperactivity/inattention, peer relationship problems, prosocial behaviour. Languages: >90 languages available. Recommended by NICE[8].	10min for caregivers + teacher. Online version available. Cost: free.	SDQ

Vineland Adaptive Behaviour Scale 3rd Edition (VABS-3)[85]	Social/ emotional development	0-90y interview/caregiver form, 3-21y teacher form also available. Caregiver/teacher questionnaires. Domains: communication (receptive, expressive, written), daily living skills (personal, domestic, numeric, community, school community), socialisation (interpersonal relationships, play and leisure, coping skills), motor skills (gross motor, fine motor), maladaptive behaviour (internalising, externalising, critical items). Languages: English, Spanish.	Up to 40-50min for caregiver interview with tester with extra sections (motor/maladaptive behaviour). 10min for teacher. Interview version available for telephone. Cost: £861.60 starter kit.	VABS-3
Visual Motor Integration (VMI, Beery-Buktenica)[86]	Motor	2-100y. Direct child assessment - screening. Short and full format tests, plus supplemental visual perception and motor coordination tests.	10-15min, up to 30min with supplemental tests. In person. Cost: £276.60 starter kit, £138 for 25 forms.	Beery VMI
Wechsler Preschool and Primary Scales of Intelligence 4th edition (WPPSI-IV)[87]	Cognitive development	2y6m-7y7m. Direct child assessment. Primary index scales: verbal comprehension index, visual spatial index, working memory index, fluid reasoning index, processing speed index. Ancillary index scales: vocabulary acquisition index, nonverbal index, general ability index, cognitive proficiency index. Recommended by NICE[8]. There is an alternative Wechsler Nonverbal Scale of Ability if required for linguistically diverse groups.	45-60min. In person. Recommended to be done by educational/clinical psychologist and/or professional with appropriate training. Cost: £1563.60 starter kit, £148.80 for 25 forms.	WPPSI-IV

All costings correct as of January 2025.

Appendix 2. Resources and groups to signpost

Resource	**Details**
PRISM Preterm Birth Information for Education Professionals[88] www.pretermbirth.info	Preterm birth information for education professionals, and caregivers. Provides free learning modules to improve knowledge of the long-term consequences of preterm birth on children's learning and development and strategies that can be used to support preterm born children in the classroom.
Prem Aware Award https://www.thesmallestthings.org/prem-aware-award	The Smallest Things charity for families of children born preterm. The charity's Prem Aware Award for schools and early years settings raises awareness of the impact of prematurity on development and learning, supports parents and carers, and helps schools to recognise and meet the specific learning needs of children born prematurely.
Bliss https://www.bliss.org.uk/parents/growing-up/starting-primary-school	Bliss charity for babies born preterm or sick, with advice pages for caregivers about starting primary school, how to delay school entry, and getting support such as benefits.
Learning about neurodiversity at School (LEANS)[89] https://salvesen-research.ed.ac.uk/leans Belonging in School[90] https://inclusion.mrc-cbu.cam.ac.uk/	Resources for mainstream primary schools to develop policies and teaching programmes around educational inclusion, particularly for learners with developmental differences.
FIZZY and Clever Hands programme[91] https://www-archive.ekhuft.nhs.uk/patients-and-visitors/information-for-patients/patient-information-leaflets/fizzy-leaflets/	A programme designed by therapists in Kent Community NHS Trust to improve fine motor, balance, and coordination through games. Designed for caregivers and teachers.
Royal Free Paediatric Occupational Therapy Tools https://padlet.com/cypotrfh/ot-tools-third-edition-3vy447afmvvwesco	A padlet of resources gathered by the paediatric occupational therapy team at the Royal Free London NHS Foundations Trust. Contains advice, strategies, and equipment ideas to support children to develop independence in everyday skills in early years and school-age children.
Strategies for children with attention difficulties in school https://www.lambethschoolspartnership.uk/Article/Download/87F09D29-3DB8-4DDC-A7B8-21A577CFC35C	A leaflet from Guys and St Thomas NHS Foundation Trust, Lambeth Local Authority, and South London and Maudsley NHS Trust. This describes strategies to reduce the impact of attention difficulties in the classroom and school.
Information and resources to support coordination and motor skills https://www.cambspborochildrenshealth.nhs.uk/services/cambridgeshire-childrens-occupational-therapy-service/online-learning-and-training/co-ordination-and-motor-skills https://www.cambspborochildrenshealth.nhs.uk/child-development-and-growing-up/hand-skills/	Resources from the Cambridgeshire Children's Occupational Therapy Service to develop motor coordination skills and fine motor skills.

Appendix 3: An example of good practice: A four-year follow-up clinic

Dr Monica Negoita, Leeds Community Healthcare

Background

This is a Leeds citywide pathway offering enhanced neurodevelopmental assessments at age 4 years to all children born extremely premature before 28 weeks' gestation, running monthly since April 2022, following an evidenced and pragmatic business case to local commissioning services including a clear recognition of local resources, staffing, training requirements and admin support.

How are eligible children identified and invited to this clinic?

A clear admin pathway was developed to ensure the right children were selected and invited, and their follow up and/or referrals are processed correctly. Children are identified based on birth gestation, information required at GP registration. All children who were born before 28 weeks' gestation and who live in Leeds at age 4 years, regardless of their place of birth, are invited. Parents are given a summary of the potential risks associated with extreme prematurity, a basic description, and the benefits of our offer, with opt in instructions. Children who are already known to the Leeds paediatric neurodisability services are not invited, because the level of input, assessments, interventions, and support is already high.

A training package was developed for community paediatric nursing colleagues, including resources around local support to share with families. Difficulties with sleep, behaviour, emotional immaturity, restricted eating, constipation are some of the commonly highlighted areas.

This is an assessment service, and the option to monitor certain children who are doing well but have borderline developmental skills in a second appointment is included in our pathway. Children who need longer term follow up, more investigations, or MDT input are referred to the Paediatric Neurodisability service.

What are parents expected to do ahead of this clinic?

Parents first opt in to the service after the initial offer letter. Admin staff contact them to offer a suitable in-person clinical appointment between 45 and 51 months.

Prior to the appointment, parents are asked to complete two questionnaires – the ASQ-3 (via post) and SDQ (electronic form submitted directly into the child's electronic patient record, SystmOne). These capture parental views and allow parents time to reflect on the child's skills and progress ahead of the clinic appointment.

What does it involve?

The clinic is run by a paediatrician and senior nurses with experience in neurodevelopmental follow-up. A nurse obtains growth measurements, collects paper questionnaires, and then scores the ASQ-3 SDQ. Consent is obtained to share information with other teams.

We discuss the child's specific neonatal risk factors, current parental concerns, the child's health, and developmental progress to date, followed by areas to monitor, further assessments and interventions planned. The child undergoes a focused developmental assessment and medical examination by the paediatrician and community paediatric nurse. We use 1:1 play-based interaction and the SOGS II, with focus on any specific difficulties identified.

A summary of discussions, developmental assessments, any investigations, referrals and planned follow up is then included in a report we share with the family, GP, and the child's neonatal unit. We encourage families to share this report with the child's education providers.

If the child is identified to have specific difficulties likely to impact their engagement and progress in education settings, we gain parental consent to share a Health Education Notification summarising the child's needs with Leeds Special Educational Needs and Inclusion Team (SENIT). If the clinician requires additional information from other settings to clarify difficulties, consent is gained to contact the child's educational provider separately after the appointment.

Further early reflections and plans:

We aim to expand our remit to other children at risk of neurodevelopmental problems. We are working with the Leeds neonatal team to synchronise neurodevelopmental follow-up offers for children born preterm from neonatal unit discharge until school age. We are planning to gather parental feedback to inform service development.

We are also continuing work with the Leeds SENIT and SEND coordinators to optimise communication and raise awareness about the potential complications of extreme prematurity.

Appendix 4: An example of a business case for preterm infant follow-up

The problem the scheme will solve, or the opportunity it will exploit

NICE guideline [NG72] covers the developmental follow-up of babies, children and young people under 18 years who were born preterm and specifies what extra assessments and support children born preterm might need during their growth and development. This proposal covers the work streams identified for Leeds Community Healthcare (LCH) as a result of NG72.

- Neurodevelopmental follow up (FU) at 4 years of all Leeds babies <28 weeks gestation.

1. The aims and objectives of the scheme

To provide the required developmental assessment by LCH integrated into current Community Paediatric Neuro-disability Clinics (PND). The requirement of the general development assessment is as follows:

- A general development assessment by a "paediatrician with expertise in neurodevelopment" (NG72 section 1.4).
- Pre assessment including a Strengths and Difficulties Questionnaire (SDQ), Ages and Stages Questionnaire (ASQ), a standardised test for IQ (e.g WISC Version 4) (see section 3: intended approach), and a record review of assessments from other professionals involved with the child, including the 2 year check.
- An offer of orthoptic vision screening.

➢ **Estimated cohort**

Based on retrospective numbers it is understood that the cohort size for Leeds babies <28 weeks gestation is approximately 50 children per year. An audit of cases 2011-2015 suggests an expected annual increase in the cohort of between 5 and 10%.

2. The intended approach of the scheme (if known)

New assessments would be integrated into the current Community PND clinic pathway. Assessment would be undertaken through the following process:

i. Referral to Community Eye Service for check prior to appointment (and query Audiology).
ii. Child attends clinic for pre-assessment by a Nurse or Specialist Health Visitor – to include SDQ, ASQ, functional assessment and collation of information.
iii. Child attends PND clinic for general development assessment by a Paediatrician – onward referral as required.

<u>IQ testing</u> – This is a requirement of NG72 however is not included in the proposed offer as it is recommended that the case would be discussed with an educational psychologist or clinical psychologist as appropriate following assessment, as opposed to specific testing. The impact of IQ testing needs to be assessed, and would be explored in the next stage of a business case, as this offer is not in line with current local practice and inclusion could further increase demand. Specific IQ testing (as stipulated in NG72) if required will require a separate business case for funding.

3. The intended outcomes/benefits of the scheme

- Practice in line with NICE guidance.
- Identification of deficits in learning, attention, motor control and other processing at an earlier stage to plan intervention and improve outcomes.

4. Potential risks and obstacles.

- Recruitment to substantive medic capacity and impact on mobilisation start date/costs if locum is required.
- A structured screen will pick up more needs than a functional assessment. The cohort of children would not usually be referred to PND clinicians when they were older as the deficits are subtle deficits in learning, attention, motor control and other processing difficulties that would not be identified. An increase in referrals are anticipated in audiology and vision screening and other areas of functioning i.e. attention for CAMHS, motor and speech & language difficulties, leading to increased demand for therapies (SLT, Physiotherapy and Occupational Therapy) as well as for Education Services (Early Years Team).
    - The costs of the proposal do not account for increase in demand on to other pathways and this is proposed as a later business case for investment once impact can be better assessed and demonstrated. The additional costs of vision and query hearing screening as part of the pathway will be included in the next stage of the proposal if assessed as additional demand.
- Without appropriate level of investment as outlined in previous point the proposal could impact on the current offer and ability to meet 18 week wait times.
- Due to subtle presentation children may not meet current thresholds for CAMHS and the system will need to consider how these children are catered for (would anticipate they will show up on the behavioural pathway) and future need for a specific offer for this cohort.

5. Costs:

Indicative costs based on Sept 2019 start date (on assumption of confirmation of funding by end Dec 2018). Based on 4.25 hours of clinical input and associated clinical administration (from medic, nurse or health care support worker) plus administration.

Cohort	19/20	20/21	21/22
FU at 4 years of babies <28 weeks gestation	£11,049 29 cases	£20,898 54 cases	£22,852 58 cases

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