NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Developmental follow-up of children and young people born preterm

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 12 October 2017

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for developmental follow-up of children and young people born preterm. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

Developmental follow-up of children and young people born preterm NICE guideline 72 (2017).

Next review: August 2020.

2 Overview[1]

2.1 Focus of quality standard

This quality standard will cover the developmental follow-up of babies, children and young people under 18 years who were born preterm (before 37^{+0} weeks of pregnancy).

2.2 Definition

Preterm birth is defined as birth before 37 weeks' gestation. Preterm birth is associated with an increased risk of developmental problems and disorders. These include developmental challenges, physical, sensory, cognitive and learning disorders, and emotional and behavioural problems. These may extend into adolescence and, in some cases, be lifelong. In particular, the risk and prevalence of impairments that affect educational attainment rise sharply in children born before 28 weeks' gestation. Although most major disorders are detectable in the first 2 years of

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[1] Unless referenced as from another source, the information in this section is from Developmental follow-up of children and young people born preterm NICE guideline NG72 (2017)

life, several developmental disorders and problems, particularly those that have an impact on the child's ability to participate and on their educational attainment, may not be apparent until they are older.

2.3 Incidence

The Office for National Statistics 2015 data on birth characteristics reports that the proportion of preterm births in England and Wales was 7.6%. This amounted to 53,209 preterm births from a total of 697,797 live births, of which 3014 (6% of preterm births and 0.4% of all births) were before 28 weeks' gestation. The highest percentage of births before 37 weeks gestation occurred in the Black Caribbean ethnic group, with 10.7% of births being classed as preterm. The White Other ethnic group had the lowest percentage of preterm births, with 6.6% of live births occurring before 37 weeks gestation.

2.4 Management

Identifying developmental problems and disorders in all children (born preterm or at term in England) is currently done through the Healthy Child Programme (HCP), which incorporates nationally approved population screening programmes recommended by Public Health England. This includes a review at 2 years to 2 ½ years of age which includes an assessment of social, emotional, behavioural and language development.

Children born pre-term with, or who are at increased risk of, developmental problems or disorders, should have enhanced developmental support and surveillance, which is in addition to reviews done through the HCP. This includes additional advice and interventions with skilled professionals that aims to support them after discharge from hospital, respond to their concerns, and reduce the impact of any developmental problems and disorders. Surveillance includes active monitoring of a child's development, at set times and using specific tools, to detect developmental problems and disorders.

2.5 National outcome frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 Public health outcomes framework for England, 2016–2019

Domain	Objectives and indicators
1 Improving the wider determinants of health	***Objective*** Improvements against wider factors which affect health and wellbeing and health inequalities ***Indicators*** 1.02 School readiness 1.05 16–18 year olds not in education, employment or training
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities ***Indicators*** 2.02 Breastfeeding 2.05 Child development at 2–$2^1/_2$ years

Table 2 NHS outcomes framework 2016–17

Domain	Overarching indicators and improvement areas
4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4b Patient experience of hospital care *4c Friends and family test* *4d Patient experience characterised as poor or worse* *ii Hospital care* ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving people's experience of integrated care** *4.9 People's experience of integrated care*

3 Summary of suggestions

3.1 Responses

In total 15 stakeholders responded to the 2-week engagement exercise 17/08/17–01/09/17, including 1 'no comment' response.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Providing enhanced developmental support and surveillance • Providing enhanced developmental surveillance up to 2 years (corrected age) • Developmental assessment at 2 years (corrected age) • Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation	• APCP and SCM 6, BAPM, NMCRG, RCPCH, SCM 1, SSBCNODN • APCP and SCM 6, BAPM, RCPCH, SCM 2, SCM 3, SCM 4 • BAPM, RCPCH, SCM 1, SCM 2, SCM 4, SCM 5, SSBCNODN
Multidisciplinary team	• Bliss, BAPM, RCOT, SCM 1, SCM 5, SSBCNODN
Information and support • Information and support for parents and carers of all preterm babies • Sharing information with services	• APCP and SCM 6, Bliss, BAPM, NCD, NMCRG, SCM 1, SCM 2, SCM 3, SCM 4, SCM 5 • Bliss, SCM 2, SCM 3, SCM 4, SSBCNODN
Additional areas • Audit, reporting and measures • Staff training • Communication about follow-up • Developmental assessment practices, use of technology and therapy-led groups	• BAPM, NCD, NMCRG, RCPCH • SCM 5 • Bliss • APCP and SCM 6
APCP, Association of Paediatric Chartered Physiotherapists Bliss BAPM, British Association of Perinatal Medicine NCD, National Clinical Director NMCRG, Neonatal Medicine Clinical Reference Group RCPCH, Royal College of Paediatrics and Child Health RCOT, Royal College of Occupational Therapists SCM, Specialist committee member SSBCNODN, Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 497 papers were identified. In addition, 30 papers were suggested by stakeholders at topic engagement and 1 paper internally at project scoping.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Providing enhanced developmental support and surveillance

4.1.1 Summary of suggestions

Providing enhanced developmental surveillance up to 2 years (corrected age)

Stakeholders highlighted the importance of following up children born preterm with increased risk of developmental problems to enable early detection of any issues, and to plan any interventions needed. Stakeholders felt that there is inconsistency in identifying the children who need enhanced surveillance, the assessments used and in the number of reviews offered. Stakeholders also raised variability in diagnosing learning disabilities.

Developmental assessment at 2 years (corrected age)

Stakeholders highlighted that a face-to-face developmental assessment at 2 years for children born preterm who are having enhanced developmental surveillance is an area for quality improvement. Stakeholders felt that the assessment can identify any potential issues at an early stage so that appropriate intervention can be offered, which will improve lifelong outcomes. It was raised that not all children are having an assessment and there is high variation between neonatal networks' coverage. The importance of using a standardised assessment to ensure consistency, quality and enable comparison of developmental outcomes between services was also highlighted by stakeholders.

Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation

Stakeholders highlighted the importance of following up children born before 28 weeks up to 4 years of age, including a further assessment at 4 years. This is due to developmental problems that can impact on schooling being harder to identify and not always picked up at 2 years, or developing later, so a further check allows for these to be picked up, and support put in place, before starting school. Stakeholders suggested that follow-up beyond 2 years is not currently offered by many neonatal services.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Providing enhanced developmental surveillance up to 2 years (corrected age)	**Criteria for enhanced developmental support and surveillance up to 2 years (corrected age)** NICE NG72 Recommendation 1.3.1 **Providing enhanced developmental support** NICE NG72 Recommendation 1.3.4 **Providing enhanced developmental surveillance up to 2 years (corrected age)** NICE NG72 Recommendation 1.3.6
Developmental assessment at 2 years (corrected age)	**Providing enhanced developmental surveillance up to 2 years (corrected age)** NICE NG72 Recommendation 1.3.6 **Developmental assessment at 2 years (corrected age)** NICE NG72 Recommendation 1.3.11
Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation	**Criteria for enhanced developmental support and surveillance at 4 years (uncorrected age)** NICE NG72 Recommendation 1.3.3 **Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation** NICE NG72 Recommendation 1.3.13

Providing enhanced developmental surveillance up to 2 years (corrected age)

Criteria for enhanced developmental support and surveillance up to 2 years (corrected age)

NICE NG72 Recommendation 1.3.1

Provide enhanced developmental support and surveillance by a multidisciplinary team (see section 1.4) up to 2 years (corrected age) for children born preterm who:

- have a developmental problem or disorder or
- are at increased risk of developmental problems or disorders, based on the following criteria:
  - born before 30^{+0} weeks' gestation or
  - born between 30^{+0} and 36^{+6} weeks' gestation and has or had 1 or more of the following risk factors:
    - a brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
    - grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
    - neonatal bacterial meningitis
    - herpes simplex encephalitis in the neonatal period.

Providing enhanced developmental surveillance up to 2 years (corrected age)

NICE NG72 Recommendation 1.3.6

For all children born preterm who are having enhanced developmental surveillance, provide as a minimum:

- 2 face-to-face follow-up visits in the first year that focus on development, at the following corrected ages:
    - between 3 and 5 months **and**
    - by 12 months

  and

- a detailed face-to-face developmental assessment at 2 years (corrected age) (see recommendation 1.3.11).

Developmental assessment at 2 years (corrected age)

NICE NG72 Recommendation 1.3.11

Provide a face-to-face developmental assessment at 2 years (corrected age) for children born preterm who are having enhanced developmental surveillance. This assessment should include as a minimum:

- all aspects listed in recommendation 1.3.7
- using the Parent Report of Children's Abilities – Revised (PARCA-R) to identify if the child is at risk of global developmental delay, learning disability (intellectual disability) or language problems:
    - if the PARCA-R is not suitable (for example, because of poor English language comprehension or the child being outside the validated age range of 22 to 26 months), use a suitable alternative parent questionnaire
- Gross Motor Function Classification System (GMFCS) score if cerebral palsy has been diagnosed
- ensuring that checks of vision and hearing have been carried out in line with national recommendations.

Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation

Criteria for enhanced developmental support and surveillance at 4 years (uncorrected age)

NICE NG72 Recommendation 1.3.3

Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28^{+0} weeks' gestation (see recommendation 1.3.13).

Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation

NICE NG72 Recommendation 1.3.13

Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28^{+0} weeks' gestation that includes as a minimum:

- all aspects listed in recommendation 1.3.7
- using the following parent questionnaires, to be completed by parents or carers beforehand and the results discussed during the assessment:
  - the Strengths and Difficulties Questionnaire (SDQ), to check for social, attentional, emotional and behavioural problems
  - the Ages and Stages Questionnaire (ASQ) 48-month questionnaire, to check for various aspects of development
- reviewing previous assessments and information from all other relevant sources
- using a standardised test to assess IQ, such as the Wechsler Preschool and Primary Scales of Intelligence 4th Edition (WPPSI) test
- GMFCS score if cerebral palsy has been diagnosed
- ensuring that the child has been offered orthoptic vision screening as recommended by the National Screening Committee.

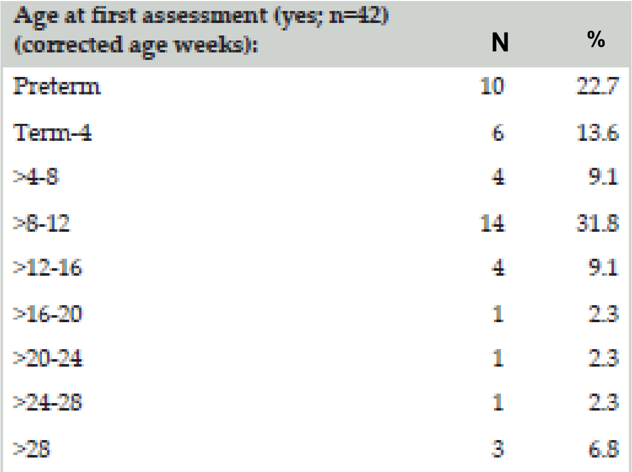
4.1.3 Current UK practice

Providing enhanced developmental surveillance up to 2 years (corrected age)

A study that investigated current UK physiotherapists' practice in neurodevelopmental follow-up assessment of high-risk infants used a national web-based survey to gain responses from paediatric physiotherapists working as lead clinicians for early years (infants under 2 years old) in NHS acute and community settings. Responses were only allowed when there was a local neurodevelopmental programme for high-risk infants. The inclusion criteria for all follow-up programmes included ex-preterm infants (but of varying gestational age at birth and weights), and 86% also included hypoxic ischaemic encephalopathy as a specific criteria. However, not all programmes had specific inclusion criteria. 62 respondents answered the main questionnaire and most neonatal networks provided at least 1 response.

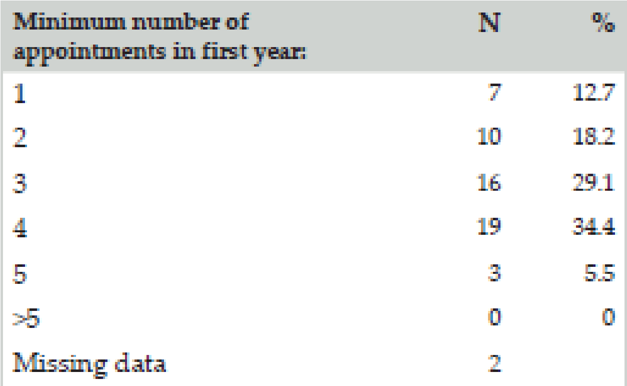
31.8% of initial assessments of high-risk infants happened when they were aged between 8-12 weeks corrected age (see table 5). The minimum number of appointments offered in the first year of life varied: 87.2% offered 2 or more appointments in the first year, with the largest proportion offering 4 follow-ups (34.4%) (see table 6). Infants were most frequently discharged between 18-24 months corrected age, where no neurodevelopmental abnormality existed (44%).

Table 5 Age at first assessment



Age at first assessment (yes; n=42) (corrected age weeks):	N	%
Preterm	10	22.7
Term-4	6	13.6
>4-8	4	9.1
>8-12	14	31.8
>12-16	4	9.1
>16-20	1	2.3
>20-24	1	2.3
>24-28	1	2.3
>28	3	6.8

Table 6 Minimum number of appointments in first year



Minimum number of appointments in first year:	N	%
1	7	12.7
2	10	18.2
3	16	29.1
4	19	34.4
5	3	5.5
>5	0	0
Missing data	2	

The study also found that 89.1% of physiotherapists were using standardised assessments at least sometimes within follow-up programmes. Of these, 79.6% used more than 1 assessment tool. The most popular assessment was the AIMS (72.9%), with the Bayley Scale of Infant Development Version – III (BSID-III) (62.5%) and GMsA (35.4%) also frequently used.

Developmental assessment at 2 years (corrected age)

The National Neonatal Audit Programme (NNAP) 2017 Annual Report on 2016 data recorded the number of babies born at less than 30 weeks gestation for whom a 2 year (corrected age) health status follow-up had been partially or fully completed. It found that:

- Of the 4023 eligible babies, 61% had some/all health data entered, 64 babies were recorded as being lost to follow up and 39% of babies had no 2 year follow-up health data reported to the NNAP at all. This figure has improved by only 0.8% since 2015, despite both a relevant active CQUIN in England, and the emphasis given by NHS England to this measure in 2016.
- Only 9 units reported 2 year follow-up health data of 100% of babies discharged home from their unit.
- Some networks have greatly improved their performance (Wales: 31% in 2015; 59.5% in 2016), but others have shown a decline in performance (Thames Valley Wessex: 85% in 2015; 76% in 2016).
- Only 1358/4023 (34%) eligible infants had a standardised assessment performed as part of their 2 year follow up, in comparison to 36% in 2015.
- 56% of eligible babies with health data entered had their developmental outcome categorised using data from a standardised assessment. This varied from 28% of babies with data recorded in Yorkshire and Humber Neonatal Operational Delivery Network (ODN), to 86% for Peninsula and Western Neonatal ODN.
- Bayley assessments were performed most commonly but a wide range of alternative assessments, including Griffiths and Schedule of Growing Skills, were also used.

Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks' gestation

No published studies on current practice were found for this suggested area for quality improvement. Stakeholders stated that the NNAP only collecting data on outcomes to 2 years of age reflects that most neonatal follow-up services only offer assessment to 2 years (corrected age).

4.1.4 Resource impact

During the development of NG72 NICE determined that there would be no significant resource impact from implementing the guidance.

4.2 Multidisciplinary team

4.2.1 Summary of suggestions

Multidisciplinary team

Stakeholders highlighted that enhanced developmental support and surveillance of children born preterm should be delivered by a multidisciplinary team with appropriate skills. Stakeholders identified the roles that should be included in the team delivering different types of support and assessment, and the roles that should be easily accessible when needed, such as allied health professionals.

4.2.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Multidisciplinary team	**Delivering enhanced developmental support and surveillance** NICE NG72 Recommendations 1.4.1 to 1.4.4

Multidisciplinary team

NICE NG72 Recommendation 1.4.1

Enhanced developmental support and surveillance for children born preterm who meet the defined criteria (see recommendations 1.3.1 to 1.3.3) should:

- be provided as an integral part of a neonatal service working together with local health services
- empower parents and carers to be involved in decisions about their child's care
- be delivered by a multidisciplinary team with the necessary skills (see recommendation 1.4.2)
- record outcomes at specified time points for national audit (see section 1.5)
- be monitored by checking adherence to the recommendations in this guideline, including follow-up rates and outcomes, as part of the routine provision of neonatal care by neonatal operational delivery networks and commissioners.

NICE NG72 Recommendation 1.4.2

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include professionals with knowledge and expertise in the following areas:

- neonatal care
- development of children born preterm, including developmental problems and disorders (see recommendation 1.3.8)
- providing support in the community, for example for feeding problems
- administering and interpreting results from questionnaires and standardised tests (for example, the PARCA-R, SDQ, ASQ and IQ tests such as the WPPSI)
- collating information from a range of sources to facilitate decision-making and writing reports
- local care pathways, including Early Years education.

NICE NG72 Recommendation 1.4.3

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include the following professionals:

- for enhanced developmental support:
    - neonatologist or paediatrician with an understanding of neonatal care and child development
    - outreach nurse or nurse with expertise in the development of babies born preterm

- for the surveillance assessments up to and including 2 years (corrected age) (see recommendation 1.3.6):
    - neonatologist or paediatrician with an understanding of neonatal care and child development
    - at least one of occupational therapist, physiotherapist and speech and language therapist
- for the surveillance assessment at 4 years (uncorrected age) (see recommendation 1.3.13):
    - educational or clinical psychologist
    - paediatrician with expertise in neurodevelopment.

NICE NG72 Recommendation 1.4.4

Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should have access to the following professionals:

- community nurse or health visitor
- occupational therapist
- physiotherapist
- speech and language therapist
- paediatric neurologist
- dietitian.

4.2.3 Current UK practice

Multidisciplinary team

The Bliss baby report 2015 includes results from a survey sent in May 2015 to the 161 neonatal units in England that were operational during 2014/15. 101 (63%) units responded. The report found that there is wide variation in access to allied health professionals across different units, with many unable to meet national standards. This includes 43% (38 out of 89) of units who did not have any access to an occupational therapist and 12% (11 out of 91) who could not access a speech and language therapist, even via referral to another service. One neonatal intensive care unit said that babies had no access to a dietitian, an occupational therapist, a speech and language therapist, or a specialist radiographer.

The study of UK physiotherapists' practice in neurodevelopmental follow-up assessment of high-risk infants found that:

- A variety of professional disciplines were involved in follow-up programmes. All programmes included either a neonatologist (59.7%), community paediatrician (32.3%) or a hospital paediatrician (27.4%).
- Physiotherapists were the largest single group represented on follow-up programmes (91.9%). Five (8.1%) participants reported that there was no physiotherapist present within the programme.
- Occupational therapists (30.6%) and dieticians (25.8%) were groups also often involved in programmes.
- Most commonly physiotherapists were always present at follow-up sessions (n=45, 72.6%).
- The reasons provided for no physiotherapist being present at sessions were that there was insufficient funding and/or capacity in the physiotherapy service (n=3) and that follow-up was done separately at the hospital (n=3).

4.2.4 Resource impact

During the development of NG72 NICE determined that there would be no significant resource impact from implementing the guidance.

4.3 Information and support

4.3.1 Summary of suggestions

Information and support for parents and carers of all preterm babies

Stakeholders suggested discharge planning and helping parents and carers of preterm babies to leave hospital with the knowledge and skills they need to look after their baby at home are a priority. Stakeholders felt that information should be provided about ongoing support and follow-up arrangements, the risks of developmental problems and outcomes after preterm birth, and how to access help if there are any concerns. Stakeholders felt that offering tailored information that is communicated sensitively, as well as emotional and psychological support, is important but not always provided.

Sharing information with services

Stakeholders suggested that information on any developmental problems identified at the 2 year and 4 year assessments, and information on a child’s premature birth, should be shared with education services. Stakeholders felt that education professionals should be aware of the late presentation of problems and that sharing information would improve schools’ understanding of the impact of preterm birth on development and learning. It was also felt that it would enable educational planning and management for preterm children to improve their academic outcomes. Stakeholders highlighted that there is currently no formal system for sharing information between health and education services. Feeding back developmental outcomes to neonatal services to inform review of services and allow more accurate counselling of parents was also raised.

4.3.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the committee’s discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Information and support for parents and carers of all preterm babies	**Providing information and support** NICE NG72 Recommendations 1.1.2, 1.1.3, 1.1.5 and 1.1.6 **Information and support leading up to and on discharge home** NICE NG72 Recommendations 1.1.7 to 1.1.14 **Providing enhanced developmental support** NICE NG72 Recommendation 1.3.4
Sharing information with services	**Information sharing and referral** NICE NG72 Recommendation 1.3.15 **Later presentation of learning or behavioural problems** NICE NG72 Recommendation 1.3.16

Information and support for parents and carers of all preterm babies

Providing information and support

NICE NG72 – Recommendation 1.1.2

Provide information about the risk and prevalence of developmental problems and disorders in babies born preterm (see section 1.2) to parents or carers, and offer to discuss this with them.

NICE NG72 – Recommendation 1.1.3

Provide information to parents or carers of preterm babies that is tailored to their individual circumstances, taking into account:

- their child's potential developmental needs
- their level of education
- any social care needs they have
- any cultural, spiritual or religious beliefs
- the need for consistency in information sharing among healthcare professionals.

NICE NG72 – Recommendation 1.1.5

Provide emotional and psychological support to parents or carers of preterm babies as needed, recognising the significant potential impact of having a preterm baby on all the family. Times when support may be particularly valuable include:

- when the baby is transferred between units or hospitals

- leading up to and on discharge home.

NICE NG72 – Recommendation 1.1.6

Provide information to parents or carers of preterm babies about opportunities for peer support.

Information and support leading up to and on discharge home

Discharge planning and support

NICE NG72 – Recommendation 1.1.7

Start discharge planning as soon as possible after the birth of a preterm baby, and involve parents or carers at all stages.

NICE NG72 – Recommendation 1.1.8

Before discharging a preterm baby:

- agree a discharge plan with the parents or carers
- ensure that the discharge plan includes clear information about any antenatal and perinatal risk factors for developmental problems and disorders (see section 1.2)
- share the written discharge plan with parents or carers and with primary and secondary healthcare teams.

NICE NG72 – Recommendation 1.1.9

Help parents or carers to gain the knowledge, skills and confidence they need to look after their baby at home and to support the baby's developmental needs, taking into account that they are likely to be anxious about caring for their baby after discharge. This may relate to:

- interaction with the baby
- managing feeding
- patterns of sleeping
- physical positioning of the baby, including safe sleeping
- impact on day-to-day living, such as social isolation because of fear of infection.

NICE NG72 – Recommendation 1.1.10

Involve the social support networks (which may include partners, grandparents or other family members) of parents or carers of a baby born preterm when planning discharge and during follow-up.

Information before discharge about ongoing support and follow-up

NICE NG72 – Recommendation 1.1.11

Inform parents or carers of all preterm babies about the routine postnatal care and support available, as described in the NICE guideline on postnatal care up to 8 weeks after birth.

NICE NG72 – Recommendation 1.1.12

Explain to parents and carers of preterm babies about:

- universal services and national recommendations for assessing the development of all children through screening (for example, newborn hearing screening) and surveillance (including social, emotional, behavioural and language development) and
- whether their baby will also be offered enhanced developmental support and surveillance (see section 1.3) and plans for follow-up.

NICE NG72 – Recommendation 1.1.13

Explain to parents or carers that their child's developmental (corrected) age, which is calculated from their original due date (and not the date they were born), will be used for the first 2 years when assessing their functional and developmental skills (such as walking and talking).

NICE NG72 – Recommendation 1.1.14

Advise parents or carers to talk to their health visitor or GP if they have any concerns about their child's development at any stage of childhood or adolescence.

Providing enhanced developmental support

NICE NG72 Recommendation 1.3.4

Provide parents or carers of a preterm baby having enhanced developmental support with a single point of contact within the neonatal service for outreach care after discharge.

Sharing information with services

NICE NG72 Recommendation 1.3.15

If findings at any stage of developmental surveillance, including the assessments at 2 years (corrected age) and 4 years (uncorrected age) (see recommendations 1.3.11 and 1.3.13), suggest any developmental problems or disorders:

- share information with:
    - parents or carers
    - primary and secondary healthcare teams
- refer the child to an appropriate local pathway for further assessment
- ask parents or carers for permission to share the information with:
    - education services
    - social care services as appropriate.

Later presentation of learning or behavioural problems

NICE NG72 Recommendation 1.3.16

Primary and secondary education professionals should be aware that:

- preterm birth may be a factor in learning or behavioural problems
- these problems can emerge at any point during a child or young person's education
- prompt referral to educational support services may be needed.

4.3.3 Current UK practice

Information and support for parents and carers of all preterm babies

The Bliss baby report 2015 found that 61% (59 out of 96) of units surveyed were able to provide a community outreach service. The majority of the units who do not provide this service themselves said that some community support is available for babies after they are discharged, for example from a children's community nursing team, community midwives or health visitors. However, some of the units reported that the outreach staff do not have neonatal training. It also reported that:

- 41% (38 out of 93) of neonatal units said that parents had no access to a trained mental health worker (such as a clinical psychologist, psychotherapist, trained counsellor or another professional with mental health training) – either on the unit or via referral to services outside of the unit.
- At 30% (28 out of 93) of units, parents had no access to psychological support at all. Even parents with the most critically ill babies are often not able to access this support.

- One third (10 out of 30) of neonatal intensive care units were not able to offer parents access to a trained mental health worker and around 1 in 8 (4 out of 30) were unable to provide any psychological support.

The NNAP 2017 Report included information on senior neonatal unit staff meeting with parents within the first 24 hours after their baby's admission. The report found that:

- There had been further improvement in the proportion of families who were documented as seen by a senior member of the neonatal team within 24 hours of their baby's admission (88% in 2015; 90% in 2016).
- One in ten admissions overall had no documented consultation with parents within 24 hours after the baby's admission. In 1 in 17 of documented cases (5.9%) this was because the unit had indicated that this consultation did not occur.
- 33 units met this standard for 100% of eligible babies admitted while 7 units met the standard for fewer than 80% of their eligible babies.
- Two networks (Thames Valley and Wessex ODN (Thames Valley) and Thames Valley and Wessex ODN (Wessex)) had the highest rates of adherence to this audit measure in both 2015 and 2016.
- Midlands South West ODN performed least well in this audit measure in both 2015 and 2016, however it did improve its adherence to the standard by 8% across those years.

The Neonatal Survey 2014 assessed parents' experiences of neonatal care at 88 hospital neonatal units from 72 NHS trusts in England (including special care baby units, local neonatal units and neonatal intensive care units), in addition to the neonatal services at Jersey General Hospital. A total of 15,944 eligible parents were sent a questionnaire. Responses were received from 6000 parents, a response rate of 37.6%. The average findings can be seen in the charts below.

Chart 1 Staff on the neonatal unit, involvement in care and information and support

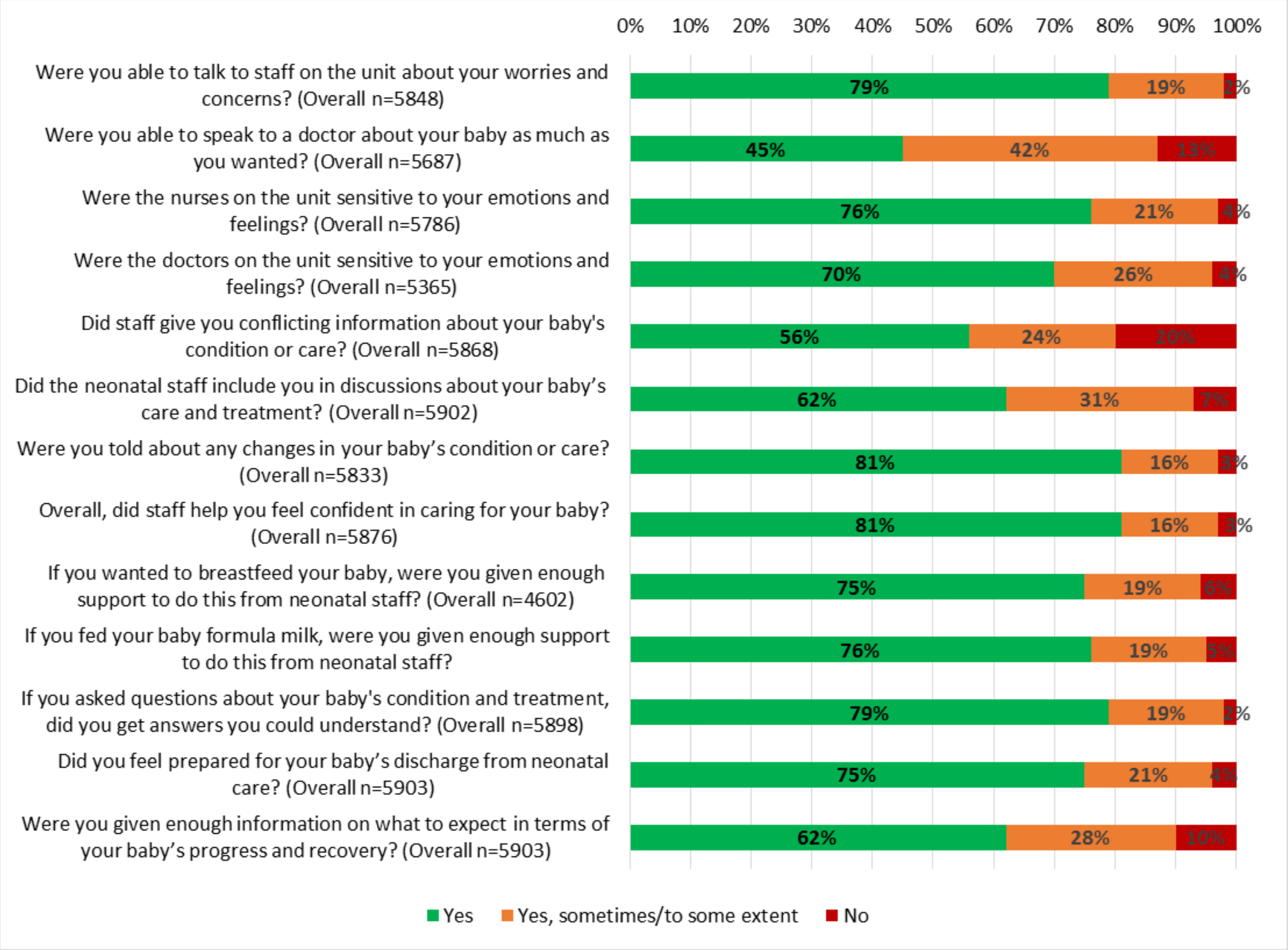


Chart 2 Information and support for parents: written information

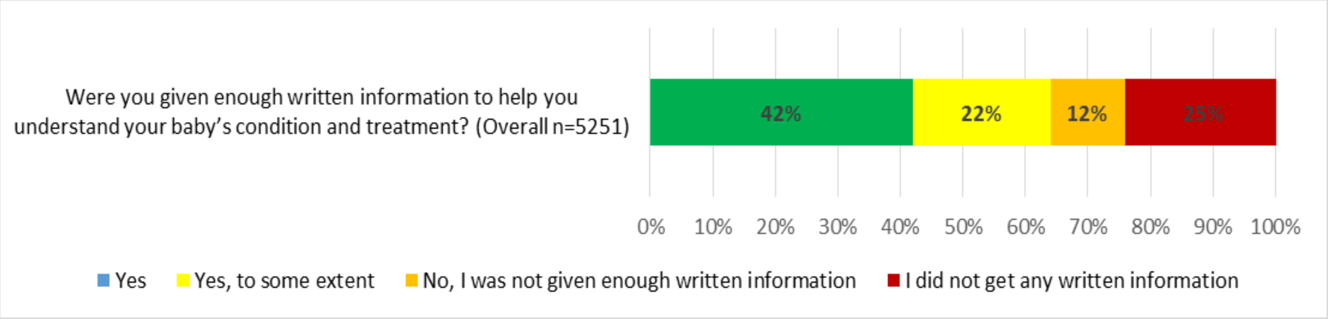


Chart 3 Information and support for parents: emotional support or counselling

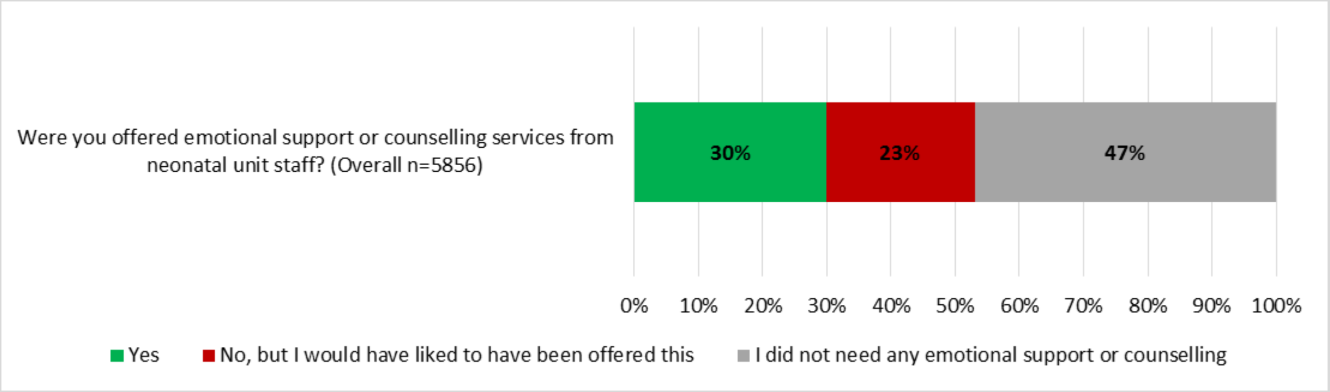
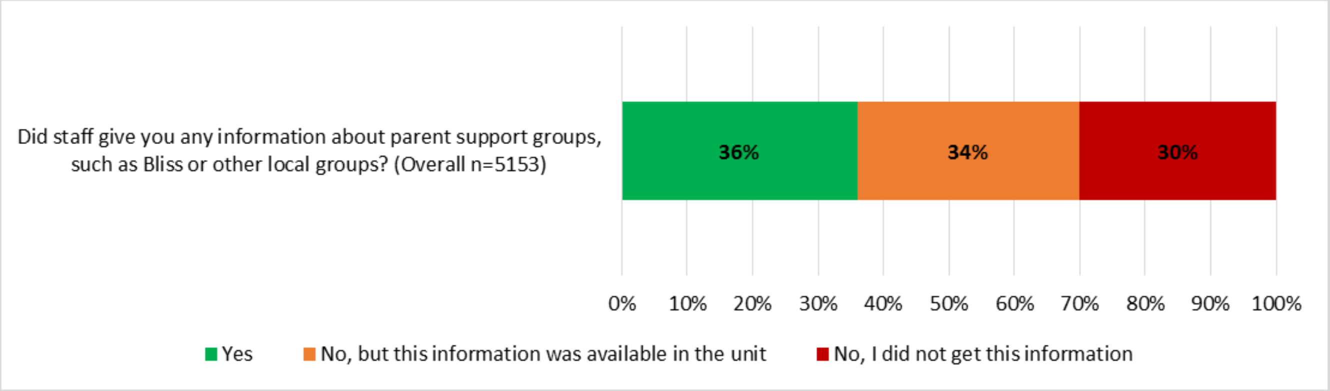


Chart 4 Information and support for parents: information about support groups



Sharing information with services

No published studies on sharing information between services were found; this area is based on stakeholder's knowledge and experience.

Current practice information was found on education professionals' knowledge of outcomes following preterm birth in a survey of teachers and educational psychologists. The survey was completed by 585 teachers and 212 educational psychologists. Responses were scored and a total knowledge score (range 0–33) was computed (higher scores indicate greater knowledge); 830 staff responded to the school survey, of whom 734 (88%) were teaching staff; 70 (8%) non-teaching staff and 4% were excluded due to missing demographic data. The results were as follows:

- The average knowledge score for teaching staff was 14.7 (range 0–27). This equated to an average accuracy (i.e. the proportion of correct responses) of 45%; 15 (2.6%) scored 0 and 12% responded with <25% accuracy.
- The average total knowledge score of educational psychologists was 17.1 (range 1–28), equating to 52% accuracy; 11 (5.2%) responded with <25% accuracy and no one scored 0.
- Compared with data of neonatal clinicians obtained in a previous study (n=70, mean 26.0), both teaching staff and educational psychologists had significantly

lower scores, with average deficits of 11.2 and 8.9 points respectively. Teaching staff in schools for children with special educational needs (SEN) had significantly higher scores than those in mainstream schools.

- Only 8% of teachers knew that maths difficulties are a particular deficit after preterm birth, and 88% held the erroneous belief that most very preterm children will experience developmental delays as a toddler. Only 11% to 18% knew that very preterm children are likely to be inattentive and have poorer peer relationship skills than term-born children. Psychologists also displayed 11% to 18% accuracy in these areas.
- In both groups greatest accuracy was demonstrated on items relating to neurosensory sequelae such as cerebral palsy and the need for assistance with activities of daily living.
- Only 38% of teaching staff felt adequately equipped to support preterm children. Over 80% of respondents requested more information about preterm birth.

The areas of poorest knowledge related to the most common adverse outcomes after preterm birth, specifically mathematics difficulties, peer relationship problems, and inattention.

4.3.4 Resource impact

During the development of NG72 NICE determined that there would be no significant resource impact from implementing the guidance.

4.4 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 12th October.

Data collection and reporting

Stakeholders suggested that neonatal data collection systems should be updated to match the NICE recommendations, and highlighted the importance of data collection and outcome reporting. Recording data on developmental assessments and monitoring adherence through the National Neonatal Audit Programme was also suggested.

These suggestions have not been progressed. Participation in audit and collation of information are methods by which quality improvement can be evidenced. Quality statements focus on the delivery of care or support, not the methods by which evidence is collated. However, audits and suggested methods of data collection may be referred to in the data sources for quality measures.

Staff training

A stakeholder suggested that health visitors, paediatricians and neonatologists need training on the developmental needs of children born preterm, and this should be included in the curriculum. Quality statements on staff training are not usually included in quality standards as healthcare professionals involved in assessing, caring for and treating children born preterm should have sufficient and appropriate training and competencies. Training may enable quality improvement to take place but is not considered as a quality improvement area. It is also outside NICE’s remit to influence the content of national curriculums.

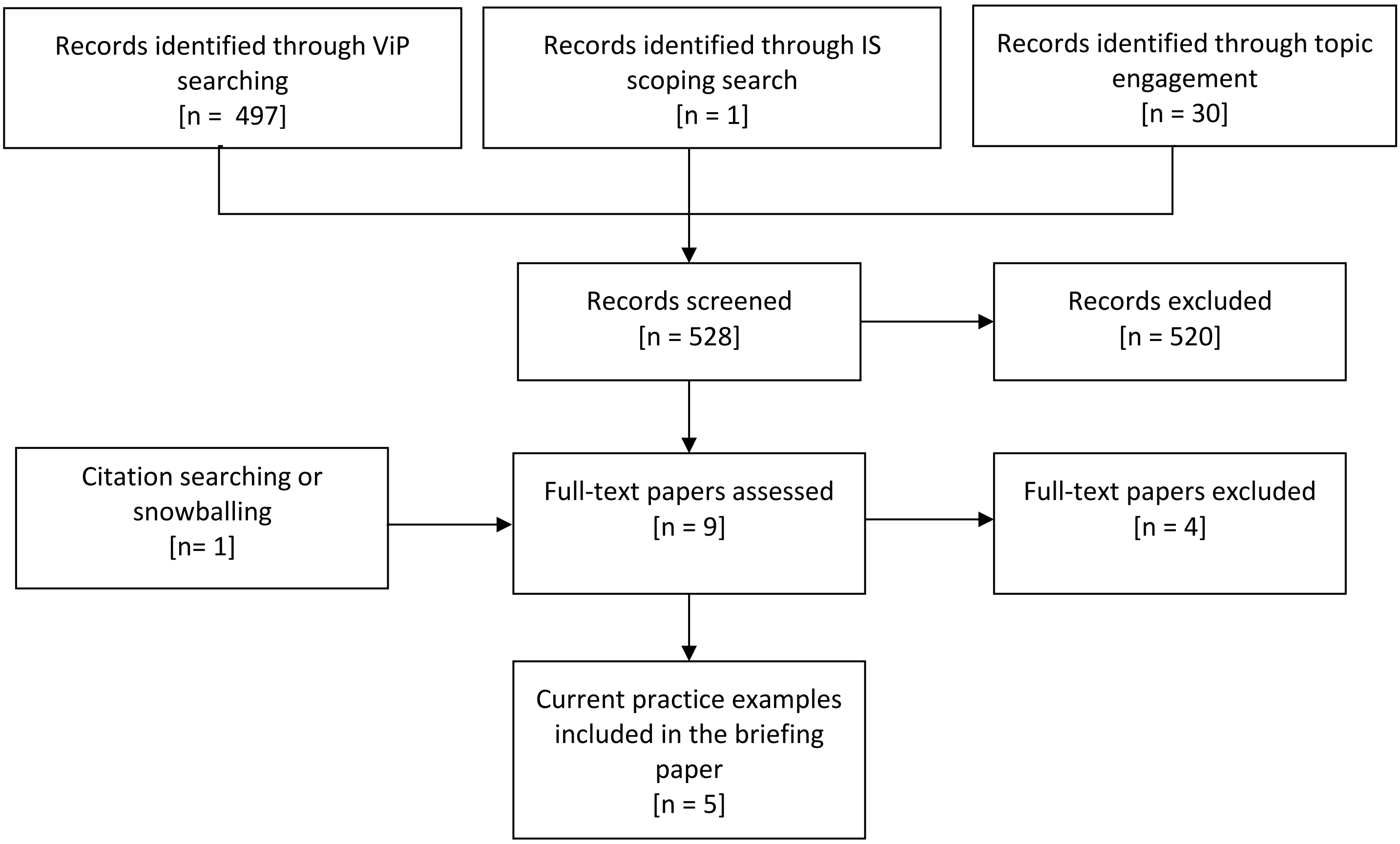
Communication about follow-up

A stakeholder suggested that hospitals need to improve the process of contacting parents for follow-up, such as by using different methods of communication, like email and text, and having a minimum number of times they should try to contact them. Making sure that it is clear which hospitals carry out follow-up, and that GPs and health visitors know which babies will receive enhanced support was also raised. There are no recommendations on this area within the development source (NICE guideline NG72).

Developmental assessment practices, use of technology and therapy-led groups

A stakeholder suggested areas on developmental assessment practices, use of technology and therapy-led groups. There are no recommendations on these areas within the development source (NICE guideline NG72).

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
General comments					
1	Royal College of Nursing	The RCN has no comments to submit to inform on the Developmental follow-up of children and young people born preterm quality standards topic engagement at this time.			
4.1 Providing enhanced developmental support and surveillance					
Providing enhanced developmental surveillance up to 2 years (corrected age)					
2	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Early, accurate diagnosis of neurodevelopmental sequelae	There is good evidence that this can enable: Parents to be able to adjust earlier Prepares / sets up parent expectations –Including receiving information and support Enables timely referral for early intervention for infant and potentially for the parent Early intervention promotes better long term outcome	Use of accurate prognostic assessment tools now more available and should be incorporated into common systematic practice e.g. GMsA, HINE combined with MRI for id of cerebral palsy Example in Australia ref Novak et al 2017, early intervention services now routinely creating streaming of infants at high-risk of cerebral palsy from 3-4 months of age GMsA prognostics considered in need of early intervention	(Margot Bosanquet, Lisa Copeland, Robert Ware, & Roslyn Boyd, 2013; Brogna et al., 2013; McIntyre, Morgan, Walker, & Novak, 2013; Novak, Morgan, Adde, & et al., 2017; Rentinck, Ketelaar, Jongmans, & Gorter, 2007; D. M. M. Romeo et al., 2008; Schuengel et al., 2009; Spittle et al., 2016) See: BAPM STANDARDS FOR HOSPITALS PROVIDING NEONATAL INTENSIVE AND HIGH DEPENDENCY CARE 2001 See: Published parental questionnaires Bracht M, Inwood S, Hussey-Gardner B, et al Parent perceptions of an NICU

					follow-up clinic. Neonatal Network: The Journal of Neonatal Nursing 1998;17:47-8 Examples of good practice: High risk follow up clinics run by the same staff members ensures consistency of approach, early diagnosis, improved attendance rates, up skills staff quickly and builds better relationships with families. (Edinburgh Royal Infirmary)
3	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Comprehensive, systematic and equitable follow-up	Consider literature of defining 'high-risk' infant – co-morbidities relationship with developmental sequelae – ensure these factors are incorporated into follow-up pathways-programmes	Research highlights need to identify follow-up cohorts from preterm population based upon given risk factors e.g. outlined in NICE guideline There is wide variability across NHS providers – families may travel to level 3 neonatal unit for in-patient care where there is a comprehensive follow-up programme but be transferred locally close to discharge where there is inadequate follow-up.	See NICE guidelines: Developmental follow-up of children and young people born preterm See: BAPM STANDARDS FOR HOSPITALS PROVIDING NEONATAL INTENSIVE AND HIGH DEPENDENCY CARE 2001 See NHS Toolkit for high quality Neonatal Services 2009 Other refs: (Beaino et al., 2010; Harniess P.A. & Nikopoulou-Smyrni P., 2015; Himpens et al., 2010; Moore T et al., 2012) In addition to entering outcome data on national database, services should be encouraged

					to develop more comprehensive/ detailed databases to maintain systematic overview, increase reporting locally including through research/ audit and enable contribution to the National Neonatal Audit Program. (NNAP)
4	British Association of Perinatal Medicine (BAPM)	Children born preterm before 30+0 weeks of gestation and those born between 30+0 to 36+6 weeks' gestation with risk factors for developmental problems are provided enhanced developmental support and surveillance up to 2 years of corrected age			
5	Neonatal Medicine Clinical Reference Group (CRG)	Develop quality measures for parental support offered by neonatal services (either locally or by network).	Parent support offered currently shows variation within and between providers and networks and lacks a framework for consistency of neurodevelopmental follow-up provision. This guideline provides an opportunity to improve the support received by parents of this high-risk population and assessment of this by development of quality measures.		

6	Royal College of Paediatrics and Child Health	Diagnosing learning disability	The other major issue is that of diagnosing learning disability, which again is highly variable across England. Including this in the quality standard would be extremely helpful.		
7	SCM 1	Developmental follow up at set corrected ages using specific screening tools	Recommended in NICE guidance; Evidence supports early intervention for developmental difficulties	Important to pick up on developmental problems early; plan intervention if needed; Preterm babies are at greater risk for developmental problems.	
8	Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	A minimum of 2 reviews in the first year of life and a review at 2 years, targeting developmental progress	Early intervention will provide the best possible outcome.	Inconsistency in follow up, in order for early intervention there should be a minimum number of follow up reviews in order to provide an opportunity to pick up on developmental problems early.	
9	Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	A developmental follow up service for all preterm babies <30 weeks, and those born between 30-36 completed weeks, at risk for developmental problems/disorders	Early intervention has been shown to improve outcomes.	Inconsistent approach, where assessment is carried out there are various assessments used and different health professionals undertake the assessment at various different ages.	https://www.networks.nhs.uk/nhs-networks/staffordshire-shropshire-and-black-country-newborn/documents/documents/follow-up-assessment-parent-information-leaflet-2015

Developmental assessment at 2 years (corrected age)					
10	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Consistency and high quality assessment	Use of standardised assessments widely accepted as best practice / gold standard – these assessments need to valid and reliable for preterm population, cover the different domains of development at different age points e.g. neurological assessment (e.g. HINE), functional assessments (e.g. AIMS (1st year of life), Bayley's 3mths - 24 mths) There is a need for consistent, trained and experienced MDT assessors particularly <24 months	There is evidence that use of standardised assessment use, AHP presence and length of follow-up in expert preterm developmental follow-up programmes is variable between centres and not always optimal (Harniess P.A. & Nikopoulou-Smyrni P., 2015) and including personal communications.	See NHS Toolkit for high quality Neonatal Services 2009 See: STANDARDS FOR HOSPITALS PROVIDING NEONATAL INTENSIVE AND HIGH DEPENDENCY CARE 2001 (M. Bosanquet, L. Copeland, R. Ware, & R. Boyd, 2013; Johnson & Marlow, 2006; D. M. Romeo, Ricci, Brogna, & Mercuri, 2016; D. M. M. Romeo et al., 2008)
11	British Association of Perinatal Medicine (BAPM)	Children who are receiving enhanced developmental surveillance receive face-to-face developmental assessment at 2 years of corrected age.			
12	Royal College of Paediatrics and Child Health	Medical follow up of babies born less than 30 weeks gestation at 2 years of age	Medical, physio, educational, audit, research benefits to be accrued by families and wider society	Existing evidence shows that follow up is incomplete, and varies significantly between providers and also by neonatal networks.	NNAP report – 2016 data to be published soon

				Complete follow up will be needed to achieve accurate description of outcomes at a population level. Data show that children where follow up is achieved with difficulty tend to do much worse than those who are followed up without problems in getting them to attend clinics	
13	SCM 2	Enhanced developmental support and surveillance by MDT - age 2 (as per rec 1.3.1)	Enhanced developmental support recommended in NICE guidance. It is important that development of very preterm babies is monitored after their discharge from the neonatal unit. Developmental checks at age two provide a vital opportunity to identify any potential issues at an early stage so that appropriate intervention can be offered.	40% of babies born </= 30 weeks do not have a follow up consultation at age 2 recorded (according to NNAP AR 2016). Variability between networks is very high. This means developmental issues may be missed. There are areas of good practice where follow up rates are very high.	NNAP annual report 2016 http://bit.ly/2iLu2dt Rec and evidence in NICE DFPB Guideline - 1.3.1 - 1.3.6 - 1.3.11 - 1.3.12

14	SCM 3	Providing developmental assessments and recording that assessment at 2 years corrected age for at risk preterm babies	A developmental assessment at 2 years is recommended within the NICE guideline for babies <30 weeks or with specified risk factors (Rec: 1.3.6). Developmental assessment informs parents, neonatal services and commissioners. It provides an opportunity to intervene and can identify unrecognised problems.	The national neonatal audit programme (NNAP) found that only 40% of <30 week gestation babies had a 2 year developmental assessment partially or completely recorded. Of those who had an assessment recorded there was variation in the assessment provided with a range of assessment tools used. 18% of the recorded assessments had insufficient information to indicate impairment category.	The National Neonatal Audit Programme (NNAP) is run by the Royal College of Paediatrics and Child Health. The NNAP annual report detailing clinical follow-up data can be found at http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3
15	SCM 3	Assessment of PARCA-R use as a national standard assessment tool	The Developmental Follow up of Preterm babies NICE guideline recommends a formal developmental assessment at 2 years corrected age (Rec 1.3.11) with screening for cognitive and language delay as a minimum requirement. The PARCA-R is recommended except where age or language issues preclude its use. It is a validated tool but has not been used on the scale it will be once the NICE guideline is implemented.	There are language and age restrictions on the use of the PARCA-R. This means that it may be variably applied across different geographical locations and by different neonatal follow up services. It will be useful for neonatal services, particularly those in ethnically diverse areas, to be able to assess its local utility as an assessment including as a speech delay screening tool.	The RCPCH National Neonatal Audit Programme highlights that 60% of 2 year old born <30 weeks had a developmental assessments partially or completely recorded but the assessments used varied. By recommending a standardised assessment the NICE guideline may reduce this variability. NNAP data is available at http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3

16	SCM 4	Providing developmental follow-up at 24 months corrected age for children born <30 weeks' gestation	Developmental follow-up for children born <30 weeks' gestation at 2 years of age is recommended by NICE as part of the enhanced developmental surveillance pathway (Rec: 1.3.6). There is good evidence that children born very preterm are at high risk for developmental problems that are evident in infancy and persist throughout childhood and adolescence with far reaching with consequences across the lifespan. Early referral for developmental problems may improve lifelong outcomes for very preterm children and their families and follow-up at two years should therefore be provided for the highest risk babies. There is good evidence of variation in the current quality and coverage of developmental follow-up at 2 years of age with 40% of children born <30 weeks' not having a development assessment recorded at this age.	There is high quality evidence that children born preterm are at risk for a range of developmental problems and disorders that impact on function across the lifespan (see NICE evidence reviews). There is good evidence of current variation in the number of children who receive a follow-up assessment at two years of age available from national audit data. The 2016 NNAP Annual Report identified that 40% of children born <30 weeks' gestation did not receive a follow-up assessment at this age or have outcome data recorded.	The Royal College of Paediatrics and Child Health National Neonatal Audit Programme produces an annual report detailing clinical follow-up data see: http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3

17	SCM 4	Administering a standard test of cognitive and language development for children born <30 weeks' gestation at 24 months corrected age.	The use of a formal developmental assessment for children born <30 weeks' gestation is recommended by NICE including, as a minimum, a screening test for cognitive and language delay (Rec: 1.3.11) There is good evidence that children born very preterm are at high risk for developmental problems and disorders. Early identification of problems is important to allow referral for intervention and support. Early referral may reduce the prevalence of developmental problems and improve outcomes for children and their families. It is	A recent study found that routine NHS assessments lack adequate sensitivity for identifying children with cognitive and language difficulties as opposed to motor impairments and emphasised that standardised assessments are needed to identify problems in these domains (Wong et al. The validity of standardised neurodevelopmental status assessed during routine NHS follow-up of children born <30 weeks' gestation. Arch Dis Child 2015;100(suppl A3):A47. Even where a test is administered, wide variation in the specific measure used can make it difficult to compare rates of developmental impairment and typical developmental progress between	The Royal College of Paediatrics and Child Health National Neonatal Audit Programme produces an annual report detailing clinical follow-up data: http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3

			well documented that cognitive and language difficulties are the most prevalent adverse outcomes after very preterm birth but are difficult to identify without using a screening test or developmental assessment. Variation in the tests currently used at 2 years makes it difficult to compare developmental outcomes between services for neonatal audit. A standardised approach to developmental assessment for cognitive and language difficulties may improve early identification of common problems and facilitate national neonatal audit.	services. The 2016 NNAP Annual Report identified that, among the 60% of very preterm children who received an assessment at 2 years of age, the range of developmental assessments used varied widely.	
Further developmental assessment at 4 years (uncorrected age) for children born before 28+0 weeks' gestation					
18	British Association of Perinatal Medicine (BAPM)	Children born before 28+0 weeks' gestation receive face-to-face developmental assessment at 4 years of corrected age.			
19	Royal College of Paediatrics and Child Health	Follow up after 2 years of age for extreme prems	I think this may have potential benefits for developmental and educational purposes in particular.	We strongly suspect this is not a practice that is widely adopted – We know of no units or areas which can report results for a significant proportion of their services users.	Anecdote

20	SCM 1	Minor morbidities can present at school age for some groups of preterm babies	Developmental screening should continue until at least 4 years (not-corrected) for most children born preterm	Are children born preterm starting school in the UK without having had a developmental screen?	
21	SCM 2	Enhanced developmental assessment and follow up - age 4 for babies born <28 weeks (as per rec 1.3.3)	- Children born before 28 weeks are at increased risk of learning disability, which may affect learning and achievement at school, but may not be apparent at the 2-year developmental assessment. - They are also at risk of sensory, social, attentional, emotional and behavioural problems which can go unnoticed at 2 but can have a big impact on health and wellbeing, quality of life and school performance. - Often children born extremely preterm under-perform at school but are not deemed severe enough to get a statement or attend special school.	- There is currently no standard follow up assessment at age 4 for children born <28 weeks. Identifying problems before school entry will support education planning and promote social and emotional development and attainment at school. - Children like these often fall through net between services - it's not clear who takes responsibility once you're discharged from neonatal and not routinely followed up by community services - Often it's difficult to get support from CAMHS, ed psych services and other services as criteria are not met - community services do not understand preterm birth so quality of follow up variable	Rec and evidence in NICE DFPB Guideline - 1.3.3 - 1.3.13 - 1.3.14

22	SCM 4	Provision of developmental assessment at 4 years of age for children born <28 weeks’ gestation	Administration of a formal developmental assessment at 4 years of age for children born <28 weeks’ gestation is recommended by NICE (Rec: 1.3.13). Children born extremely preterm are at markedly high risk for developmental problems and disorders, in particular cognitive deficits, behaviour problems and learning difficulties which have a major impact on their schooling. Unlike physical disabilities, these difficulties are more difficult to identify readily. Even if a child’s development was progressing well at 2 years of age, these problems may emerge or become exacerbated over the preschool years so assessment at 4 years of age is needed to identify difficulties in these areas. Assessment at 4 years of age will also be informative for educational planning and management at school entry for those children that have identified problems. Currently very few neonatal services offer follow-up beyond 2 years of age so this has the potential to significantly improve care for this population of children.	There is good evidence that children born extremely preterm are at highest risk for poor educational outcomes (e.g., Quigley et al. Early and late preterm birth are associated with poorer school performance at age 5 years. Arch Dis Child Fetal Neonatal Ed 2012;97:F167-F173 & Mackay et al. Gestational age at delivery and special educational need. Retrospective cohort study of 407,503 school children. Plos Med 2010;7:e1000289). Most neonatal follow-up services currently only offer assessment to 2 years corrected age and this is reflected in the RCPCH National Neonatal Audit Project which collects data about outcomes only to 2 years of age (see 2016 NNAP Annual Report).	

23	SCM 5	It is a recommendation for 4 years follow-up to have an assessment which will include Educational Psychologist or Clinical Psychologist	Most hospitals might not have access to Clinical Psychology, that should be a priority Be Aware that currently many Clinical psychologists input has been to maternity services, there should be a clear role for clinical psychologists in regard of Infant mental health and for long-term follow-up	Please see NICE recommendation	
24	Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	A review at 4 years of age for those born <28 weeks gestation to assess special educational needs by appropriately trained health care professionals	Babies born <28 weeks gestation are at greater risk of developmental problems/having special education needs. This would provide an opportunity to put arrangements in place prior to starting school.	Assist parents in accessing educational support for their child with the child's needs having been identified in order for schools to put arrangements/support in place.	

4.2 Multidisciplinary team					
25	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Consistency and high quality assessment	Use of standardised assessments widely accepted as best practice / gold standard – these assessments need to valid and reliable for preterm population, cover the different domains of development at different age points e.g. neurological assessment (e.g. HINE), functional assessments (e.g. AIMS (1st year of life), Bayley's 3mths - 24 mths) There is a need for consistent, trained and experienced MDT assessors particularly <24 months	There is evidence that use of standardised assessment use, AHP presence and length of follow-up in expert preterm developmental follow-up programmes is variable between centres and not always optimal (Harniess P.A. & Nikopoulou-Smyrni P., 2015) and including personal communications.	See NHS Toolkit for high quality Neonatal Services 2009 See: STANDARDS FOR HOSPITALS PROVIDING NEONATAL INTENSIVE AND HIGH DEPENDENCY CARE 2001 (M. Bosanquet, L. Copeland, R. Ware, & R. Boyd, 2013; Johnson & Marlow, 2006; D. M. Romeo, Ricci, Brogna, & Mercuri, 2016; D. M. M. Romeo et al., 2008)
26	Bliss	Key area for quality improvement 3	Clarity of implementation	There needs to be improved communication as to which hospital carries this out the follow-up appointment (the discharging hospital may not where they spent the most amount of time). This needs to be communicated to parents very clearly at discharge and making sure that the hospital that carries out the follow-up has appropriately trained and skilled staff to carry out the assessment. Equally NICE needs to communicate with HVs and GPs of this guideline and which babies this affects. This is so they can refer or tell parents to contact the hospital if they have been contacted directly themselves or	Bliss is unaware of any neonatal standards or audit programmes which specifically define and measure quality of communication to parents, and between neonatal unit and community based practitioners (like Health Visitors or GPs).

				encourage them to go if they have been contacted.	
27	British Association of Perinatal Medicine (BAPM)	Networks, Commissioners and Providers of specialist neonatal care ensure access to multi-disciplinary specialist teams to support enhanced developmental support and surveillance. There is also a need to update the NNAP reference to 2017 report on 2016 data			
28	Royal College of Occupational Therapists	More occupational therapists employed in developmental follow-up services for children born preterm.	Over the past two decades there has been a significant shift in the provision of neonatal services to encompass individualised developmental care and family-centred care models. These shifts have meant the realisation of the valuable contribution of occupational therapists working in neonatal and early intervention services. The fragility of the preterm or high-risk infant means that early expected co-occupations and the development of a reciprocal	While occupational therapists are working in some existing neonatal and follow-up services, it is acknowledged that it is an emergent role. Scope exists for occupational therapists to make further contributions in these settings as set out in the practice guideline *Occupational therapy in neonatal services and early intervention* (RCOT Aug 2017). The evidence-based recommendations are set out in ten categories: 1. Occupation-based assessment 2. Developmentally supportive care	Please see the Royal College of Occupational Therapists practice guideline (NICE-accredited source) published in August 2017 on Occupational therapy in neonatal services and early intervention. Available at: https://www.rcot.co.uk/practice-resources/rcot-publications/downloads/neonatal-services

			relationship with the infant will be affected (Price and Miner2009). Raina et al (2005) reported that in these situations, it is imperative to consider the effects of the situation on both the parent and child and promote interventions that support the occupations of the family as a whole. As the infant is discharged from the neonatal unit and grows older, ongoing intervention and/or guidance provides continued opportunities to support the development of infant occupations around self-care, learning and play. Through educating parents on strategies to support and engage their child with appropriate motor experiences, occupational therapists can provide building blocks for developmental progression and parent-child interaction. <u>References</u>: • Price P, Miner S (2009). Learning to promote occupational development through co-occupation. *Journal of Occupational Science, 16(3),* 180–186. • Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD,	3. Pain management 4. Skin-to-skin (kangaroo) care 5. Positioning 6. Infant feeding 7. Parent engagement 8. Parent support 9. Identifying developmental concerns; And 10. Early intervention (Recommendations 26-31). For example recommendation 29 (RCOT 2017), is based on evidence that the provision of an early intervention model that focuses on the child’s participation in family routines and activities, shows improved attainment of functional skills for children at risk of, or with, developmental delay when compared with a traditional early intervention home visiting model (Hwang et al 2013). <u>References</u>: Royal College of Occupational Therapists (2017) *Occupational therapy in neonatal services and early intervention: practice guideline.* London: RCOT. **Hwang AW, Chao MY, Liu SW (2013) A randomized controlled trial of routines-based early intervention for children with or at risk for**	

			Russell, D.,.. Wood E (2005) The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115(6),* e626–e636.	**developmental delay. *Research in Developmental Disabilities, 34(10),* 3112–3123.**	
29	SCM 1	Developmental screening should be done by skilled professionals	Developmental screening until aged 2yrs should be completed by AHP professional able to address all areas of development together with paediatrician rather than dividing the child between several professions.	Need to consider infant/child holistically and not as separate developmental areas;	
30	SCM 5	Ensure 2 years follow-up are done by Neonatologists/ Paediatricians AND AHPs who are able to advice parents to improve outcome for the children	Many subtle difficulties can be seen during 2 years follow-up assessment, a questionnaire alone will not help improve the outcome, these are screening clinics, and we should be able after the face to face assessment and the questionnaire to advice parents regarding the next step or how to help their child	To improve outcome, our focus should be prevention and Intervention NOT Just Auditing outcome, auditing drive services and it will improve outcome indirectly, but there is a risk of doing the minimum to fulfil an audit not to improve outcome.	
31	SCM 5	It is a recommendation for 4 years follow-up to have an assessment which will include Educational Psychologist or Clinical Psychologist	Most hospitals might not have access to Clinical Psychology, that should be a priority Be Aware that currently many Clinical psychologists input has been to maternity services, there should be a clear role for clinical psychologists in regard of Infant mental health and for long-term follow-up	Please see NICE recommendation	

32	Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	Access to multi-disciplinary specialists as appropriate to support the follow up service	Where intervention has been identified as being needed this needs to be acted upon quickly with easy access to SALT, physiotherapy, etc.	Inconsistent access to specialists or long waits meaning intervention is delayed.	
4.3 Information and support					
Information and support for parents and carers of all preterm babies					
33	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Family Centred Communication	Quality of communication is very common parental priority in preterm population including importance of:	Healthcare communication is identified in all qualitative research with parents for preterm infants as a primary indicator of quality in care and is often not optimal, this particularly applies to developmental follow-up – see POPPY report as example	See NICE guidelines: Developmental follow-up of children and young people born preterm
			- Sensitive communication of difficult information - Accessible open information sharing, including written / alternative sources: educational and regarding service provision - Identified expert neurodevelopment MDT team from neonatal unit – introduced to parents - Parents empowered with knowledge/ information are more likely to seek out support		See Poppy report: http://www.nna.org.uk/html/POPPY_Family%20centered%20care.pdf (Brett, Staniszewska, Newburn, Jones, & Taylor, 2011)

					Use of information supplementary to written education or service provision. Consider technology; apps e.g. BabyBuddy, Trusted charities – social media e.g. Bliss, DVD e.g. Small Wonders Examples of good practice: Therapist led community high-risk baby groups for education and supplementary monitoring of identified infants (Hackney and Barnet).
34	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Low threshold to re-access specialist assessment and intervention services	Some neurological deficits including cognitive and behavioural difficulties may present later in life especially around school age. Families need to be empowered with information to seek out relevant services if later issues occur where it has not been possible to detect these earlier Education for professionals screening at later stages needed including health visitors, education providers	Later difficulties are well documented but can potentially be overlooked by professionals working with ex-preterm children in different settings.	(Arnaud, Daubisse-Marliac, White-Koning, & et al., 2007; Caesar et al., 2016; Johnson & Marlow, 2006; Moore T et al., 2012)

35	Bliss	Key area for quality improvement 1	Communicating about development follow up with parents	One of the main reasons why hospitals are not carrying out as many 2yr follow up appointments as they should is because parents are not fully aware that their baby will need one. Communication before discharge needs to be improved, so that parents understand that they will be contacted in the future and not to be worried or scared should the hospital be in touch. Parents also need to understand that should their contact details change they should contact the hospital so they can be contacted in the future.	NNAP data clearly shows that many hospitals are not following up with the appropriate cohort of babies: Details of how these measure will be recorded upcoming NNAP datasets can be found here on pp.35-38 http://www.rcpch.ac.uk/system/files/protected/page/NNAP%202016%20and%202017%20Audit%20Measures%20-%20web_0.pdf
36	British Association of Perinatal Medicine (BAPM)	The parents of preterm babies receive a written discharge plan with follow-up arrangements.			
37	National Clinical Director	Develop quality measures for parental support offered by neonatal services (either locally or by network)			

38	Neonatal Medicine Clinical Reference Group (CRG)	Develop quality measures for parental support offered by neonatal services (either locally or by network).	Parent support offered currently shows variation within and between providers and networks and lacks a framework for consistency of neurodevelopmental follow-up provision. This guideline provides an opportunity to improve the support received by parents of this high-risk population and assessment of this by development of quality measures.		
39	SCM 1	Consider caregiver mental health when screening infant development	NICE quality standard Ante and Postnatal Mental Health supports assessing the mother's mental health pre and post pregnancy; Be aware of other caregivers; fathers also at risk for mental health changes post birth of baby.	Having a preterm baby adds additional stress and increases a woman's risk for PPMD hence this should be screened at each developmental check; caregiver mental health can impact attachment and infant development.	
40	SCM 1	Parents/Caregivers should be given 'just the right' amount of information at each visit	As per NICE guideline on patient experience parents/caregivers should be given appropriate information to support the care of their infant/toddler	Parents may feel overwhelmed if given too much information that is not immediately relevant; should be clearly written and address current concerns, questions; Detailed 'home programs' are not always helpful and can increase stress levels hence any recommendations should be able to be incorporated into daily care and not an additional program.	

41	SCM 2	Providing information and support to parents and carers of preterm babies about risk of developmental problems and disorders tailored to their individual circumstances - start discharge planning with parents/carers asap after the birth of a preterm baby - agreed, written discharge plan information about ongoing support and follow up	Parents must be empowered to take the lead in their baby's care from the moment they are admitted to neonatal unit. This is crucial for achieving the best long-term outcomes.	Parents do not always receive a detailed written discharge plan. This needs to be shared with them and primary and secondary care teams involved with their baby. Parents need to know about follow-up and the importance of attending appointments so that appointments do not come out of the blue.	Rec and evidence in NICE DFPB Guideline - 1.1 - 1.1.8 1.1.12

42	SCM 2	Provide emotional and psychological support to parents or carers of preterm babies as needed, recognising the significant potential impact of having a preterm baby on all the family. Times when support may be particularly valuable include: - when the baby is transferred between units or hospitals - leading up to and on discharge home.	Parental mental health and wellbeing is critical to allow them to properly care for the developmental needs of their preterm baby. Providing psychosocial care and support to the family is as important as providing medical care and developmental support to the baby.	The many stresses faced by parents in NICU mean they are at higher risk of depression and anxiety compared with parents of healthy, full-term babies. This can affect their relationship with their baby and have a long-term impact on their baby's development.	Rec and evidence in NICE DFPB Guideline 1.1.5

43	SCM 2	Help parents or carers to gain the knowledge, skills and confidence they need to look after their baby at home and to support the baby's developmental needs, taking into account that they are likely to be anxious about caring for their baby after discharge. This may relate to: - interaction with the baby - managing feeding - patterns of sleeping - physical positioning of the baby, including safe sleeping - impact on day-to-day living, such as social isolation because of fear of infection	Parents must be empowered to take the lead in their baby's care from the moment they are admitted to neonatal unit. This is crucial for achieving the best long-term outcomes. Support to gain the knowledge, skills and confidence they need to look after their baby both in the neonatal unit and when they go home should be made available from the very beginning by e.g. availability of occupational therapists or family centred care specialists on the neonatal unit	Parents often deal with services following discharge which which do not understand neonatal care or prematurity. Community services need to be adequately equipped to deal with the developmental needs of preterm babies	Rec and evidence in NICE DFPB Guideline - 1.1.9 1.1.15

44	SCM 3	Providing enhanced developmental support	The NICE guideline highlights that parents of a preterm baby are likely to be anxious about caring for their baby after discharge. The Developmental Follow up of Preterm Babies NICE guideline recommends (Rec 1.1.2) that parents are given information about long term outcomes and follow up arrangements. However, the vast majority of preterm babies fall outside the criteria for enhanced developmental surveillance.	There is widespread variation across neonatal services in the provision of outreach support services and how those services are provided. Parental representation to the NICE Developmental Follow up of Preterm Babies guideline strongly valued a point of contact with the neonatal service to discuss their concerns about their baby after discharge. They wanted to be able to discuss with someone with experience of caring for preterm babies. A greater understanding of how much support is needed and how much parents would like alongside what is practically achievable is needed.	In their 2015 report (http://www.bliss.org.uk/babyreport) the premature baby charity BLISS found only 61% of neonatal units were able to provide community outreach support despite the NHS England service specification *Neonatal Critical Care* (https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e08/) making it clear that community support should be provided by an integrated hospital community neonatal team, or an identifiable team of community health professionals who have neonatal training.
45	SCM 4	Providing parents with information about long term outcomes after preterm birth and follow-up arrangements	This is recommended in the NICE Guideline (Rec: 1.1.2). Parents may not be aware of the potential impact of preterm birth on children's development, behaviour and learning. Understanding the risk for and range of likely problems may help parents spot signs of difficulties and seek support early. This is especially important where problems may be	There is a wealth of high quality evidence that children born preterm are at risk for a range of developmental problems and disorders (see NICE evidence reviews). There is documented evidence of variation in the content and timing of neonatal follow-up services which includes provision of information for parents. E.g., the NNAP 2016 Annual Report states that 40% of babies born <30	The Royal College of Paediatrics and Child Health National Neonatal Audit Programme produces an annual report detailing clinical follow-up data: http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3

			subtle and less directly observable, e.g., in terms of cognitive deficits, social-communication problems and internalising behaviour problems which are the most common adverse outcomes after preterm birth and which may have a significant impact on child and family function. Even where early development progresses well, difficulties may emerge later over the preschool years and especially at school age. Parents should be aware of these to identify problems and help obtain support for their child at school. Providing information about follow-up services may engage parents in follow-up for their child and improve current rates of attendance at follow-up appointments.	weeks gestation had a recorded follow-up consultation. There are no national information resources for parents about the long term effects of preterm birth and thus there is inconsistency in information provision. As far as I am aware babies born ≥30 weeks' gestation are rarely followed up and thus unlikely to receive information about potential long term difficulties their child may face.	
46	SCM 5	Information leaflets for parents of children born preterm, ensure it is also to be given on Postnatal ward for those not admitted to Neonatal units	Children born between 32-36 weeks gestation, have no routine follow-up by neonatologist, we know they have problems but parents not aware of it, children born at 34 weeks or above might not be admitted to Neonatal unit	Please see literature included in NICE guideline on Late preterm, e.g. McKay's paper Scotland	

Sharing information with services					
47	Bliss	Key area for quality improvement 4	There is strong evidence that premature birth is linked to behavioural problems and poorer educational attainment, and that these effects worsen with decreasing gestational age. The NICE Guideline on Developmental Follow up for Children and Young-People born pre-term makes it clear that, with permission, information should be shared into educational pathways as ‘prompt referral’ may be needed.	Information regarding a child’s premature birth is not routinely passed on to educational professionals as standard, and there is no consistent framework for alerting educational professionals to the fact that a child in their class may have been born premature.	Bliss is unaware of an area where information, with parental permission, regarding a child’s pre-term birth and development is routinely shared into an educational pathway.
48	Bliss	Key area for quality improvement 5	There is strong evidence that premature birth is linked to behavioural problems and poorer educational attainment, and that these effects worsen with decreasing gestational age. The NICE Guideline on Developmental Follow up for Children and Young-People born pre-term makes it clear that primary and secondary education professionals should be aware that preterm birth can affect learning and development and that these problems may emerge at any point during a child or young person’s education. They	There is no routine teacher-training which highlights the impact of prematurity on learning and development. As such, many teachers are unaware that behavioural problems are linked to a child’s preterm birth which in turn means children are not referred to the correct support.	Evidence for inconsistency in teacher understanding can be found here: http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12683/abstract;jsessionid=A7EB1937DC49E69766D148E3B649965F.f02t01

			also need to be aware that prompt referral to support services might be necessary		
49	SCM 2	Late presentation of learning or behavioural problems	Primary and secondary education professionals should be aware of the late presentation of problems in children born preterm		Rec and evidence in NICE DFPB Guideline 1.3.16
50	SCM 3	Linking health and educational information. Specifically linking developmental assessment outcomes and Early years foundation stage and key stage 1 attainment	Sharing information between health and education is recommended in the Developmental Follow up of Preterm Babies NICE guideline (Rec 1.3.15). This NICE guideline flags up an increased risk of lower early years and key stage 1 attainment amongst those born preterm. There is evidence that educational outcomes, especially in maths, relate to long term socioeconomic outcomes	This will allow enhanced counselling by clinical staff, allow more focused identification of problems and allow intervention to be more targeted. It may help parents have conversations with education providers about their child’s developmental issues and needs. It will help inform education staff of the developmental issues faced by preterm babies; currently this is an area that many teachers are not well informed about.	There is no current system for health and education services to share information and link relevant data e.g. results of developmental assessments and educational attainment.

51	SCM 3	Feedback of developmental outcomes to neonatal services	A feedback loop of developmental outcomes allows clinicians to give more accurate counselling to parents on neonatal units who want prognostic information and counselling about their babies future. It informs the appropriateness of intensive care for the extremely fragile preterm infant. It also allows services to identify if they are an outlier in terms of their developmental outcomes which should prompt clinicians to review their services clinical practices.	We know that survival amongst extremely preterm infants ≥24 weeks has improved whilst the proportion of those with disability is fairly static. New treatments appear regularly in neonatal intensive care and an understanding of their long term effects is vital.	A clear and well documented example of developmental outcomes informing neonatal care is the impact of postnatal steroid use for chronic lung disease and its association with increased cerebral palsy rates. Clear short term respiratory improvement led to a frequent use of post natal corticosteroids in the 1990s. When developmental follow up showed an association between postnatal steroid use and an increased risk of cerebral palsy steroid there was a marked reduction in postnatal corticosteroid use. Without the feedback of developmental outcomes to neonatal care this would not have been found. The use of lower dose, shorter course steroid regimes are currently being trialled and both respiratory and developmental outcomes will be important. Information on survival following extreme prematurity and the proportion of survivors with disability can be found in the EPICure studies and data is summarised on their website. http://www.epicure.ac.uk/

52	SCM 4	Sharing of information between health and education services	Sharing of information between health and education services is recommended in the NICE guideline (Rec: 1.3.15).	There is evidence that education professionals lack knowledge and training about the long term impact of preterm birth on children's development, learning and performance at school (see Johnson S et al. The long term consequences of preterm birth: What do teachers know? Dev Med Child Neurol 2015;57:571-577.) There is also a large and growing body of evidence of the adverse impact of preterm birth on children's educational outcomes (e.g., Quigley et al. Early and late preterm birth are associated with poorer school performance at age 5 years. Arch Dis Child Fetal Neonatal Ed 2012;97:F167-F173; Mackay et al. Gestational age at delivery and special educational need. Retrospective cohort study of 407,503 school children. Plos Med 2010;7:e1000289).	

			There is good evidence that, even in the absence of diagnosed disorders, children born preterm are at risk for a wide range of cognitive and behavioural difficulties that impact on their achievement at school. Preterm born children have poorer academic attainment and higher rates of special educational needs and learning difficulties than children born at term, which impact on their lifelong health and wellbeing. Parents frequently report that they struggle to obtain support for their preterm child in school and that schools are often unware that preterm birth is a risk factor for adverse developmental outcomes. Improved sharing of relevant clinical information and the results of developmental assessments carried out by healthcare services would aid in educational planning and management for preterm children and earlier provision of appropriate educational support to improve academic outcomes.	There is currently no formal system for sharing of information between neonatal services and early years providers or infant/primary educators prior to or at the child's initial school admission.	

53	Staffordshire, Shropshire and Black Country Neonatal Operational Delivery Network	A system of feeding special educational needs back into education pathway	An appropriate referral/communication pathway put in place in order that schools are aware of a childs needs.	A formal process would mean that all parties would be able to access the information they need in order to act in the best interests of that child and that each child would have the same opportunities.	
4.5 Additional areas					
Data collection and reporting					
54	British Association of Perinatal Medicine (BAPM)	The results of developmental assessments at 2 and 4 years of corrected age in children receiving enhanced developmental surveillance should be recorded and monitored in the national neonatal audit programme.			
55	National Clinical Director	Refine the 2 year outcome reporting on Badger to match new recommendations at 2y and 4-5y, the standard should define how these are reported			
56	National Clinical Director	National reporting of adherence (NNAP)			

57	National Clinical Director	National reporting of outcomes (? National perinatal audit or extend the MNI-CORP)			
58	Neonatal Medicine Clinical Reference Group (CRG)	Refine the 2 year outcome reporting on Badgernet to match the recommendations of the new guideline at 2y and 4-5y. The standard should define how these are reported.	Due to limitations of current neurodevelopmental follow-up provision, only 2 year outcomes are reported on Badgernet. As Badgernet is a data collection system already in place across the whole of the UK, an opportunity exists to collect and analyse robust follow-up data at minimum cost.		
59	Neonatal Medicine Clinical Reference Group (CRG)	National reporting of adherence to the new guideline.	The National Neonatal Audit Programme (NNAP) is a framework already in place to assess providers adherence to existing standards of neonatal care in the UK. This could therefore be used to assess adherence to this new guideline.		

60	Neonatal Medicine Clinical Reference Group (CRG)	National reporting of outcomes.	National reporting of neonatal mortality already occurs through MBRRACE-UK (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK) and the Maternal, Newborn and Infant Clinical Outcome Review. Reporting of neurodevelopmental outcomes is also important in this high-risk population and the new guideline provides a framework for standardisation of outcome assessment facilitating reporting nationally.		
61	Royal College of Paediatrics and Child Health	Collect population data	It would be helpful if the guideline could emphasise the need to collect population data, so that the many needs of this group are made visible. We know that reporting of diagnostic information to the Children and Young People's Health Services dataset (soon to be renamed as the Community Services Dataset) is highly variable across England at this time.		

			Using the guideline to reinforce the importance of data reporting would be helpful.		
Staff training					
62	SCM 5	For Early year staff, Health visiting, to include in their curriculum Education and training on Health and Developmental needs of children born preterm	Health visitors may not have had any paediatric or neonatal nurse training, that is causing confusion regarding recommendation and lack of consistency	Please see parents view on consistent information and how they found their health visitors not knowing about prematurity, so they loose trust	
63	SCM 5	Still regarding Information recommendation, there is lack of training for paediatricians on developmental needs for children born preterm, That should be included in Post-graduate diplomas for Neurodisability, post-graduate certificates in Paediatrics	Community paediatricians and Neurodisability consultants are the most likely paediatricians to follow-up children born preterm who present with developmental problems, there is lack of awareness and understanding regarding these children. The CCT curriculum for Neonatologists recommend attending developmental clinics and be able to perform a 2 year assessment, but that recommendation is not a must, currently not always followed	Recommendation from NICE , that the children should be followed-up by Paediatricians and AHPs who have an understanding of the developmental needs of these children.	

Communication about follow-up					
64	Bliss	Key area for quality improvement 2	Improve the process of contacting parents at 2 year follow up	Hospitals need to improve how they contact parents at time of follow-up. They need to consider using other forms of communication such as email or text to remind parents that their baby needs to attend a follow up appointment. There should be a minimum attempt of a set number of times / ways to contact these families before they realise that the appointment will not happen. Anecdotally I have heard that some units check if the baby has been seen by a local and ticked that as a follow-up assuming that any developmental issues would be raised, however this does not equate to the NICE guidelines and GPs may not be aware of what the developmental follow-up actually means.	Bliss is unaware of any set standards for the minimum number of times that a family should be contacted to arrange follow-up.

65	Bliss	Key area for quality improvement 3	Clarity of implementation	There needs to be improved communication as to which hospital carries this out the follow-up appointment (the discharging hospital may not where they spent the most amount of time). This needs to be communicated to parents very clearly at discharge and making sure that the hospital that carries out the follow-up has appropriately trained and skilled staff to carry out the assessment. Equally NICE needs to communicate with HVs and GPs of this guideline and which babies this affects. This is so they can refer or tell parents to contact the hospital if they have been contacted directly themselves or encourage them to go if they have been contacted.	Bliss is unaware of any neonatal standards or audit programmes which specifically define and measure quality of communication to parents, and between neonatal unit and community based practitioners (like Health Visitors or GPs).
Developmental assessment practices, use of technology and therapy-led groups					
66	Association of Paediatric Chartered Physiotherapists and endorsed by SCM 6	Additional developmental areas of emergent practice	**Therapy led ex-preterm groups in first 12 months (e.g. 2 sites in London)** Therapy time used to undertake Bayleys assessment to reduce staffing costs (Scotland, London) Use of Technology – developmental education for parents eg baby buddy app Early intervention for infant with emerging hemiplegia e-tips (Basu, Pearse, Baggaley, Watson, & Rapley, 2017) Use of Technology being researched for improved general movements assessment involving parents (Spittle et al., 2016)		