Neonatal specialist care

Quality standard
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# Neonatal specialist care (QS4)

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Introduction and overview

This quality standard covers the care provided for babies in need of specialist neonatal services (including neonatal special, high-dependency, intensive or surgical care services), and including transfer services.

Introduction

As a result of increasing rates of fertility and availability of assisted conception, more and more babies in England require specialist neonatal care each year. In 2007-8, one in ten babies born alive received specialist neonatal care of some sort and this number is constantly increasing. In particular, babies born pre-term require highly specialised care in units where multidisciplinary teams can ensure that they receive the best possible technologically advanced care, and that the needs of their families are also met. This quality standard provides clinicians, managers and parents with a description of what high-quality specialist neonatal care should look like.

Overview

The quality standard for specialist neonatal care requires that the physical, psychological and social needs of babies and their families are at the heart of all care given. It requires that services should be commissioned from and coordinated across all relevant agencies encompassing the whole neonatal care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to babies in need of specialist neonatal services.
Statement 1. In-utero and postnatal transfers for neonatal special, high-dependency, intensive and surgical care follow perinatal network guidelines and care pathways that are integrated with other maternity and newborn network guidelines and pathways.

Statement 2. Networks, commissioners and providers of specialist neonatal care undertake an annual needs assessment and ensure each network has adequate capacity.

Statement 3. Specialist neonatal services have a sufficient, skilled and competent multidisciplinary workforce.

Statement 4. Neonatal transfer services provide babies with safe and efficient transfers to and from specialist neonatal care.

Statement 5. Parents of babies receiving specialist neonatal care are encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff occurs throughout the care pathway.

Statement 6. Mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk.

Statement 7. Babies receiving specialist neonatal care have their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care.

Statement 8. Providers of specialist neonatal services maintain accurate and complete data, and actively participate in national clinical audits and applicable research programmes.

Statement 9. Babies receiving specialist neonatal care have their health outcomes monitored.

In addition, quality standards that should also be considered when commissioning and providing a high-quality neonatal service are listed in related NICE quality standards.
Quality statement 1: Care pathways and guidelines

Quality statement

In-utero and postnatal transfers for neonatal special, high-dependency, intensive and surgical care follow perinatal network guidelines and care pathways that are integrated with other maternity and newborn network guidelines and pathways.

Quality measure

Structure:

a) Evidence of perinatal network guidelines and care pathways for in-utero and postnatal transfers for neonatal special, high-dependency, intensive and surgical care.

b) Evidence that perinatal network guidelines and care pathways for in-utero and postnatal transfers for neonatal special, high-dependency, intensive and surgical care, are integrated with other maternity and newborn network guidelines and pathways.

c) Evidence of network arrangements to ensure that when a baby is admitted to specialist neonatal care, the mother and any multiple birth siblings can be accommodated in the same hospital during their respective admissions.

Process:

a) Proportion of babies born at less than 28 weeks of gestation who receive intensive care in a neonatal intensive care unit (NICU) within the network.

Numerator – the number of babies receiving intensive care in a NICU within the network.

Denominator – the number of babies born at less than 28 weeks of gestation within the network.

b) Proportion of babies with antenatally diagnosed fetal malformations requiring early surgery who are delivered at a designated network surgical centre.

Numerator – the number of babies delivered at a designated network surgical centre.
Denominator – the number of babies born within the network with antenatally diagnosed fetal malformations requiring early surgery.

c) Proportion of babies who are transferred back to their local neonatal unit within 24 hours of request for repatriation.

Numerator – the number of babies transferred within 24 hours of repatriation request.

Denominator – the number of babies transferred back to their local neonatal unit.

d) Proportion of babies who require neonatal surgery who receive it at a designated network surgical centre.

Numerator – the number of babies undergoing surgery at a designated network surgical centre.

Denominator – the number of babies born within the network who require neonatal surgery.

e) For singleton births: proportion of mothers who still require inpatient care when their baby is transferred to specialist neonatal care, who are transferred to the same hospital as their baby.

Numerator – the number of mothers transferred to the same hospital as their baby.

Denominator – the number of mothers who still require inpatient care when their baby is transferred to specialist neonatal care.

f) For multiple births: proportion of babies transferred to specialist neonatal care whose mother and/or multiple birth siblings are transferred to the same hospital if still requiring inpatient care.

Numerator – the number of babies whose mother and/or multiple birth siblings are transferred to the same hospital.

Denominator – the number of babies from multiple births transferred to specialist neonatal care whose mother and/or multiple birth siblings still require inpatient care.

What the quality statement means for each audience

**Service providers** ensure perinatal network guidelines and care pathways for transfers for neonatal special, high-dependency, intensive and surgical care are implemented and integrated with other
maternity and neonatal guidelines and pathways. Ensure regular monitoring of operation and effectiveness.

Healthcare professionals ensure perinatal network guidelines and care pathways are followed when transferring babies for neonatal special, high-dependency, intensive and surgical care, and invoke a report or alert mechanism where this is not possible.

Commissioners and networks ensure all eligible patients within their health economy are covered by perinatal network guidelines and care pathways for transfer for special, high-dependency, intensive and surgical care.

Parents of babies transferred to neonatal special, high-dependency, intensive or surgical care can expect the transfer to be in line with network guidelines and care pathways. These guidelines and care pathways describe specific procedures about safely transferring babies to other hospitals.

Definitions

The DH toolkit (2009) defines a network as 'linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and health board boundaries, to ensure equitable provision of high-quality, clinically effective services.'

Guidance on the content of guidelines and pathways can be found within the DH toolkit (2009) under Principles 4 and 7.

Data source

Structure: Local and network data collection.

Process: Local and network data collection
Quality statement 2: Annual needs assessments

Quality statement

Networks, commissioners and providers of specialist neonatal care undertake an annual needs assessment and ensure each network has adequate capacity.

Quality measure

Structure: Evidence of an annual needs assessment including production of an annual report covering, as a minimum, specialist neonatal activity for the network's population, monitoring of quality metrics and how concerns are being addressed.

Process:

a) Proportion of mothers whose babies required specialist neonatal care and who were booked to deliver in the network who received all their perinatal care within the network area (standard 95% as per DH toolkit [2009]).

Numerator – the number of mothers receiving all their perinatal care within the network area.

Denominator – the number of mothers whose babies required specialist neonatal care and who were booked to deliver in the network area.

b) Proportion of babies who receive specialist neonatal care in the network who are from outside the network area.

Numerator – the number of babies from outside the network area.

Denominator – the number of babies receiving specialist neonatal care in the network.

c) Bed occupancy for each level of care (standard 80% as specified in DH toolkit [2009]).

What the quality statement means for each audience

Service providers cooperate with networks and commissioners to carry out an annual specialist neonatal care needs assessment. If service provision levels are found to be inadequate, they ensure action is taken in conjunction with commissioners.
Healthcare professionals assist with specialist neonatal care needs assessments by providing accurate and validated data.

Commissioners and networks ensure that, in conjunction with service providers, an annual specialist neonatal care needs assessment is undertaken. In addition, they clearly define expected levels of service provision.

Parents of babies receiving specialist neonatal care can expect that the needs of their baby will be met by services provided in their area.

**Definitions**

Quality metrics are defined further in the DH toolkit (2009) section 5.

**Data source**

**Structure:** Local and network data collection.

**Process**

a) Local and network data collection. Contained within the Royal College of Paediatrics and Child Health National Neonatal Audit Programme.

b) Royal College of Paediatrics and Child Health National Neonatal Audit Programme collects data on whether all babies who access neonatal services are treated following their own neonatal network clinical pathway.

c) Local and network data collection.
Quality statement 3: Skilled and multidisciplinary staff

Quality statement

Specialist neonatal services have a sufficient, skilled and competent multidisciplinary workforce.

Quality measure

Structure:

a) Evidence of local arrangements to ensure specialist neonatal staff are compliant with competency levels as described by the DH toolkit (2009).

b) Evidence of local arrangements to provide a multidisciplinary service, trained and competent in the care of neonates, that has access to:

- specialist neonatal or paediatric dietitians
- specialist neonatal occupational therapists
- specialist neonatal physiotherapists
- specialist neonatal speech and language therapists
- specialist neonatal pharmacists.

Process: Proportion of completed specialist neonatal care shifts with the correct nursing and medical staffing levels as specified in the DH toolkit (2009).

Numerator – the number of shifts with the correct nursing and medical staffing levels as specified in the DH toolkit (2009).

Denominator – the number of completed specialist neonatal care shifts.

What the quality statement means for each audience

Service providers ensure specialist neonatal services are staffed in accordance with the DH toolkit (2009), and that training and competencies are regularly reviewed.
Healthcare professionals ensure they are skilled and competent for their roles and responsibilities by accessing appropriate training.

Commissioners ensure that specialist neonatal services assess and monitor the staffing levels, composition and competency of their workforce. In addition, they ensure that appropriate education programmes are commissioned.

Parents of babies receiving specialist neonatal care can expect care to be given by an appropriate number of fully trained healthcare professionals.

Definitions

Definition of a skilled and competent workforce can be found in DH toolkit (2009) Principle 2.

The process measure 'proportion of completed shifts with the correct nursing and medical staffing levels' was considered by the TEG as an appropriate measure of staffing. It is noted that this is not a mandatory data collection requirement and that collection of this data is at the discretion of local units.

Data source

Structure: Local data collection.

Process: Local data collection.
Quality statement 4: Neonatal transfer services

Quality statement

Neonatal transfer services provide babies with safe and efficient transfers to and from specialist neonatal care.

Quality measure

Structure: Evidence of network arrangements to provide a 24-hour, 7 days a week neonatal transport service with a single telephone contact.

Process:

a) Proportion of transfer teams responding to time-critical emergencies that depart from the transport base within 1 hour from the start of the referring call.

Numerator – the number of transfer teams departing from the transport base within 1 hour from the start of the referring call.

Denominator – the number of emergency transfers requests deemed time-critical.

b) Proportion of newborn babies who receive specialist neonatal care who have an admission temperature of less than 36°C.

Numerator – the number of newborn babies with an admission temperature of less than 36°C.

Denominator – the number of newborn babies receiving specialist neonatal care.

What the quality statement means for each audience

Service providers ensure a safe and efficient service for babies transferred to and from specialist neonatal care.

Healthcare professionals ensure babies receive a safe and efficient transfer to and from specialist neonatal care.
Commissioners and networks ensure transfer services are contracted and monitored to provide appropriate levels of service provision.

Parents of babies who need to be transferred to or from specialist neonatal services can expect this to be done safely and efficiently.

**Definitions**

The [DH toolkit (2009)](https://www.gov.uk/government/publications/nhs-dh-toolkit) states 'a transfer service is concerned with organising and implementing the transfer of babies and/or mothers from within a defined geographical area (network). It encompasses both users and providers, and transfers may be ex-utero or in-utero.'


**Data source**

**Structure:** Network data collection.

**Process:** a) and b) Network data collection.
Quality statement 5: Encouraging parental involvement in care

Quality statement

Parents of babies receiving specialist neonatal care are encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff occurs throughout the care pathway.

Quality measure

Structure:

a) Evidence of local arrangements to involve parents in decision-making processes.

b) Evidence of local audit demonstrating active involvement of parents in providing care for their baby.

c) Evidence of regular surveys on parent experience.

d) Evidence of local arrangements to provide bereavement services.

e) Evidence of local arrangements to provide palliative care.

Process: Parents' experience is monitored through satisfaction surveys and the evidence used to inform learning and change for improvement.

What the quality statement means for each audience

Service providers ensure a policy is in place to maintain accurate records of communication with parents of babies receiving specialist neonatal care and that parents are involved in planning and providing care. Ensure plans are in place to seek regular parental views and experience.

Healthcare professionals communicate regularly with parents of babies receiving specialist neonatal care and ensure parents are involved in decision-making and their baby's care.

Commissioners ensure services use parental feedback on involvement in decision-making and planning and provision of care to inform service improvement of specialist neonatal care.
Parents of babies receiving specialist neonatal care can expect to be encouraged and supported to be actively involved in planning and providing care, joint decision-making and to be in regular contact with their healthcare team.

**Definitions**

Support provided will depend on the parents needs and may include physical, psychological or social support.

**Data source**

**Structure:**

a) and b) Local data collection. Contained within the Picker Institute Europe's neonatal survey.

c) Royal College of Paediatrics and Child Health National Neonatal Audit Programme denominator survey Question 8: In the last 12 months has the unit carried out a parent satisfaction survey?

d) and e) Local data collection.

**Process:** A Picker Institute parent survey, developed in conjunction with Bliss, is in development and will contain questions specifically aimed at assessing parent involvement in care and decision-making.
Quality statement 6: Breastfeeding

Quality statement

Mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk.

Quality measure

Structure: Evidence of a written local policy on breastfeeding and expressing milk for babies receiving specialist neonatal care.

Outcomes:

a) Proportion of babies born at less than 33 weeks of gestation who receive specialist neonatal care who are breastfed when discharged from hospital.

Numerator – the number of babies breastfed when discharged from hospital.

Denominator – the number of babies born at less than 33 weeks of gestation receiving specialist neonatal care and discharged from hospital.

b) Proportion of babies born at less than 33 weeks of gestation who remain in hospital and still receive their mother’s breast milk at 6 weeks.

Numerator – the number of babies receiving their mother’s breast milk at 6 weeks.

Denominator – the number of babies born at less than 33 weeks of gestation, receiving specialist neonatal care and remaining in hospital at 6 weeks.

What the quality statement means for each audience

Service providers ensure implementation of a local policy on breastfeeding and expressing milk for babies in specialist neonatal care.

Healthcare professionals ensure all mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including support to express milk.
Commissioners ensure services audit their compliance against agreed standards on supporting mothers to start and continue breastfeeding, including support to express milk.

Mothers of babies receiving specialist neonatal care can expect to be offered support to start and continue to breastfeed, including support to express milk.

Data source

Structure: Local data collection. Contained within the Picker Institute Europe's neonatal survey.

Outcome:

a) Royal College of Paediatrics and Child Health National Neonatal Audit Programme produces figures on feeding status at discharge for babies born at less than 33 weeks of gestation. Also contained within the Picker Institute Europe's neonatal survey.

b) Local data collection.
Quality statement 7: Coordinated transition to community care

Quality statement

Babies receiving specialist neonatal care have their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care.

Quality measure

Structure:

a) Evidence of provision of a neonatal outreach service.

b) Evidence of multiagency discharge planning with input from community neonatal outreach services.

Process: Proportion of babies discharged from specialist neonatal care who receive an outreach service follow-up.

Numerator – the number of babies receiving outreach service follow-up.

Denominator – the number of babies discharged from specialist neonatal care requiring an outreach service follow-up.

What the quality statement means for each audience

Service providers ensure that agreements are in place for coordinating the care plans of babies receiving specialist neonatal care between relevant agencies.

Health and social care professionals ensure the care plans of babies receiving specialist neonatal care are coordinated with all relevant agencies.

Commissioners and networks ensure services are commissioned according to agreed levels of care across the specialist neonatal care pathway to enable safe and effective transition from hospital to community care.

Parents of babies discharged from specialist neonatal care can expect to receive support from health or social care professionals working in the community if their baby requires it. They can also
expect that their baby's care plan will be coordinated between relevant teams to help ensure a safe and effective transition from hospital to home.

**Data source**

**Structure:** a) and b) Local and network data collection.

**Process:** Local and network data collection.
Quality statement 8: Data, audit and research

Quality statement

Providers of specialist neonatal services maintain accurate and complete data, and actively participate in national clinical audits and applicable research programmes.

Quality measure

Structure:

a) Evidence of a documented data validation process to ensure data completeness and accuracy.

b) Evidence of participation in national clinical audits and benchmarking.

c) Evidence of participation in applicable research studies.

Process:

a) Complete and accurate data collected for the National Neonatal Audit Programme.

b) Complete and accurate data collected for the BAPM dataset.

c) Proportion of babies receiving specialist neonatal care whose parents are invited to participate in applicable research studies.

Numerator – the number of babies whose parents are invited to participate in applicable research studies.

Denominator – the number of babies receiving specialist neonatal care.

What the quality statement means for each audience

Service providers ensure accuracy and completeness of specialist neonatal data collection systems and participate in national clinical audits and applicable research programmes.

Healthcare professionals accurate record keeping and data collection.
Commissioners ensure service providers participate in agreed national clinical audits and applicable research programmes.

Parents of babies receiving specialist neonatal care can expect complete and accurate information to be kept about their baby’s care and for it to be used to improve care. They can also expect to be invited to participate in applicable research programmes.

**Data source**

**Structure:**

a) Local and network data collection.

b) Participation in Royal College of Paediatrics and Child Health National Neonatal Audit Programme.

c) National Institute for Health Research accrual system.

**Process:**

a) Royal College of Paediatrics and Child Health National Neonatal Audit Programme provides quarterly data completeness and accuracy reports to participating sites.

b) Data completeness and accuracy figures of BAPM dataset submissions.
Quality statement 9: Health outcomes

Quality statement

Babies receiving specialist neonatal care have their health outcomes monitored.

Quality measure

Structure: Evidence of processes to enable collection of health outcome data within the network for babies who receive specialist neonatal care.

Process:

a) Proportion of babies born at less than 30 weeks of gestation who received specialist neonatal care who have a 2-year outcome form completed.

Numerator – the number of babies with a completed 2-year outcome form.

Denominator – the number of babies born at less than 30 weeks of gestation receiving specialist neonatal care.

b) Proportion of babies born at 30 weeks of gestation or more who received specialist neonatal care who have a 2-year outcome form completed.

Numerator – the number of babies with a completed 2-year outcome form.

Denominator – the number of babies born at 30 weeks of gestation or more receiving specialist neonatal care.

c) Proportion of babies born at less than 32 weeks of gestation and/or with a birth weight less than 1501 g who receive specialist neonatal care and undergo retinopathy screening prior to discharge from hospital.

Numerator – the number of babies undergoing retinopathy screening prior to discharge from hospital.

Denominator – the number of babies born at less than 32 weeks of gestation and/or with a birth weight less than 1501 g, receiving specialist neonatal care and discharged from hospital.
d) Proportion of babies born at less than 32 weeks of gestation and/or with a birth weight less than 1501 g who receive specialist neonatal care who require laser surgery.

Numerator – the number of babies requiring laser surgery.

Denominator – the number of babies born at less than 32 weeks of gestation and/or with a birth weight less than 1501 g receiving specialist neonatal care.

e) Proportion of babies who received specialist neonatal care who have had a culture-positive infection of blood or cerebrospinal fluid prior to discharge from hospital.

Numerator – the number of babies who have had a culture-positive infection of blood or cerebrospinal fluid prior to discharge from hospital.

Denominator – the number of babies receiving specialist neonatal care.

f) Proportion of babies who have had neonatal encephalopathy.

Numerator and denominator under development for the National Neonatal Audit Programme.

Outcomes: a) Proportion of babies born at less than 30 weeks of gestation who receive specialist neonatal care who have no functional impairment at 2 years when corrected for gestational age.

Numerator – the number of babies with no functional impairment at 2 years when corrected for gestational age.

Denominator – the number of babies born at less than 30 weeks of gestation receiving specialist neonatal care.

b) Proportion of babies born at 30 weeks of gestation or more who receive specialist neonatal care who have no functional impairment at 2 years when corrected for gestational age.

Numerator – the number of babies with no functional impairment at 2 years when corrected for gestational age.

Denominator – the number of babies born at 30 weeks of gestation or more receiving specialist neonatal care.
c) 2-year survival rates within and compared with other networks.

*What the quality statement means for each audience*

**Service providers** ensure the health outcomes of all babies receiving specialist neonatal care are monitored.

**Healthcare professionals** ensure accurate and complete baseline data collection through pregnancy, childbirth and the perinatal period.

**Commissioners and networks** ensure specialist neonatal care health outcomes are monitored and used to inform service improvement.

**Parents** of babies receiving specialist neonatal care can expect their baby's health will continue to be assessed after discharge from hospital.

*Data source*

**Structure:** Royal College of Paediatrics and Child Health Health National Neonatal Audit Programme collects data on whether health outcomes are collected.

**Process:**

a) and b) Royal College of Paediatrics and Child Health National Neonatal Audit Programme collects data on whether 2-year outcomes are collected.

c) Royal College of Paediatrics and Child Health National Neonatal Audit Programme collects data on retinopathy screening prior to discharge from hospital for babies born at less than 32 weeks or gestation and/or with a birth weight less than 1501 g.

d) Local and network data collection.

e) Royal College of Paediatrics and Child Health National Neonatal Audit Programme will collect data on babies who have had a culture-positive infection of blood or cerebrospinal fluid prior to discharge.

f) Royal College of Paediatrics and Child Health National Neonatal Audit Programme will collect data on neonatal encephalopathy.
Outcomes:

a) and c) Network data collection.

b) Network data collection. Also contained within the Royal College of Paediatrics and Child Health National Neonatal Audit Programme.
Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the development sources section.

Commissioning support and information for patients

NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard. Information for patients using the quality standard is also available on the NICE website.

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of health and social care. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so aspirational achievement levels are likely to be 100% (or 0% if the quality statement states that something should not be done). However, it is recognised that this may not always be appropriate in practice taking account of patient safety, patient choice and clinical judgement and therefore desired levels of achievement should be defined locally.

We have indicated where national indicators currently exist and measure the quality statement. National indicators include those developed by the Health and Social Care Information Centre through their Indicators for Quality Improvement Programme. For statements where national quality indicators do not exist, the quality measures should form the basis for audit criteria developed and used locally to improve the quality of health and social care.

For further information, including guidance on using quality measures, please see what makes up a NICE quality standard.

Diversity, equality and language

During the development of this quality standard, equality issues were considered.
Good communication between health and social care professionals and the parents of babies receiving specialist neonatal care is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Parents of babies receiving specialist neonatal care should have access to an interpreter or advocate if needed.
Development sources

Evidence sources

The documents below contain clinical guideline recommendations or other recommendations that were used by the TEG to develop the quality standard statements and measures. This NICE quality standard is based on consensus documentation as there was no relevant NICE guidance or NHS Evidence accredited sources available.


Policy context

It is important that the quality standard is considered alongside current policy documents, including:

Related NICE quality standards

Patient experience in adult NHS services. NICE quality standard 15 (2012).
The Topic Expert Group and NICE project team

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Update information

Minor changes since publication

November 2016: Data sources updated in statements 2, 5, 6 and 9.
About this quality standard

NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence such as NICE guidance and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.

The methods and processes for developing NICE quality standards are described in the healthcare quality standards process guide. Please note that in the absence of NICE guidance or NHS Evidence accredited sources for this topic, the development processes could not be followed.

This quality standard has been incorporated into the NICE neonatal jaundice pathway.

We have produced a summary for patients and carers.

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Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Bliss
- British Association of Perinatal Medicine (BAPM)
- Royal College of Paediatrics and Child Health
- Royal College of Obstetricians and Gynaecologists
- Royal College of Midwives