Report on specialised children's services and QIPP

Contents

1. Executive summary

This report forms one in a series by the Specialised Healthcare Alliance looking at services prioritised by the National Specialised Commissioning Group in relation to the delivery of quality and productivity at a time of spending constraint, otherwise known as QIPP. It was particularly informed by a stakeholder workshop on specialised children's services organised by the Alliance and the South West Specialised Commissioning Group in Taunton on 8th October 2010. A wide range of stakeholders including commissioners, clinicians, other healthcare professionals and representatives from patient groups attended the workshop.

The report sets out some background information on QIPP and specialised children's services before seeking to distil the major themes explored during the workshop in relation to treatment, care and outcomes.

Given the breadth of specialised service for children, the critical importance of neonatal services to QIPP objectives, and the large proportion of specialised service budgets that neonatal services absorb, a decision was taken to focus on the early years of a child's life. It is also the case that neonatal services have significant repercussions on other children's services and that it has been prioritised in the current NHS Operating Framework.

Among the most important points to emerge, attention is drawn to:

- **Better matching of provision to need across the various levels of neonatal care.**
- **The importance of more effective team working.**
- **Greater empowerment of parents, including support for parental care at home.**
- **An openness to new models of care, such as the ambulatory care model pioneered in East & North Hertfordshire.**

These and other important themes are discussed in section 3 of the report.

2. Background

2.1 QIPP

Quality, Innovation, Productivity and Prevention (QIPP) is the flagship policy being used by the NHS to find the £15-20 billion of savings identified by Sir David Nicholson as necessary in 2011/14 as a result of rapidly rising demand for services and a challenging fiscal climate.[1]

The overall aim of the scheme is to combine improvements in quality of care with efficiency savings that can be reinvested in front-line services. Ideally, quality and productivity will go hand-in-hand, providing a better service for the patient, as well as cost savings for the NHS as a whole.[2]

The National Specialised Commissioning Group (NSCG) has prioritised ten services for taking forward the QIPP agenda, with each Specialised Commissioning Group (SCG) leading on one of the services.

In each case, the NSCG has established three main objectives in relation to QIPP as follows:

- Working through the SCG Finance Network, benchmark and demonstrate value for money in the agreed services;
- Working with the SCG Public Health Network, develop common CQUIN (Commissioning for Quality and Innovation)[3] goals for the agreed services;
- Working through the SCG Public Health Network, develop common health outcomes for the agreed services.

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The Specialised Healthcare Alliance is looking at all ten services in relation to QIPP. The Alliance's aim is to ensure a balanced discussion between the four strands of QIPP.

QIPP raises specific challenges in the context of specialised children's services. These include the range of paediatric service areas covered under specialised children's services, and the specific challenges such as parental involvement.

2.2 Children's services: policy context

Health services for children are a national priority and the subject of a National Service Framework.[4]

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[1] For background on QIPP: *The NHS quality, innovation, productivity and prevention challenge: an introduction for clinicians* (March 2010), available from here

[2] See NHS Improvement's QIPP site for more background

[3] The CQUIN payment framework makes a proportion of providers' income conditional on quality and innovation. See here for more information.

Sir Ian Kennedy has just completed his review of NHS children's services, commissioned by NHS Chief Executive Sir David Nicholson[5]. Professor Kennedy found variations in standards of care across the country, with a large number of services in need of significant improvement. He describes the data collection necessary for effective management of services as poor or non-existent in many areas of healthcare for children and young people. The findings also call for a review of how young patients are progressed from children's to adult care.

The review recommends that GPs are given additional paediatric training, and investment shifted towards children and young people's health services. Other key recommendations of the review include:

- The creation of a single point of responsibility for children's health and wellbeing, linked in to other public services used by children, with an identified funding stream for their health and healthcare.
- A shift of investment by the NHS, especially towards early years and mental health, to improve lives in the long-term, as well as improve cost effectiveness.
- A focus on prevention, early intervention and wider well-being instead of the current model of treating illness and injury.
- Responsibility for policy relating to children's healthcare and wider well-being be brought together
- Professionals caring for children should train together, to a common curriculum.

Following Sir Ian's report, Health Secretary Andrew Lansley has published an engagement document[6]. This sets out what the recent White Paper will mean for children, and explores how the challenges Sir Ian poses can be better tackled in future.

2.3 Overview of specialised children's services

While most children are able to receive appropriate care from their primary care services and their local hospital, some have serious or complex needs that need to be dealt with by specialised paediatric health services provided in specialist centres.

Specialised children's services are distinct in that they are based on age rather than a specific treatment area or condition. They therefore encompass a range of treatment areas as applied to children. The national definition[7] identifies 23 service areas that should be regarded as specialised paediatric health services. In addition, 19 other definitions in the National Definitions Set cover both adults and children, and hence certain specialised paediatric services.

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[4] *The National Service Framework for Children, Young People and Maternity Services* (2004), available from here

[5] *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs* (September 2010), available from here

[6] *Achieving Equity and Excellence for Children* (September 2010), available from here

[7] Definition No. 23 of the third edition of the Specialised Services National Definitions Set (SSNDS) published in 2010, available from here

Specialised paediatric service areas covered in the national definition
1. Specialised Paediatric Anaesthesia and Pain Management Services 2. Specialised Paediatric Cancer Services (paediatric oncology, malignant haematology and cancer surgery services) 3. Specialised Paediatric Cardiology and Cardiac Surgery Services 4. Specialised Paediatric Dentistry Services 5. Specialised Paediatric Ear, Nose and Throat Services 6. Specialised Paediatric Endocrinology and Diabetes Services 7. Specialised Paediatric Gastroenterology, Hepatology and Nutritional Support Services 8. Specialised Paediatric Gynaecology Services 9. Specialised Paediatric Haematology Services (excluding malignant haematology, bleeding disorders and haemoglobinopathies) 10. Specialised Paediatric Intensive Care Services 11. Specialised Paediatric Mental Health (Tier 4 CAMHS and Forensic) Services 12. Specialised Neonatal Care Services 13. Specialised Paediatric Neurosciences Services 14. Specialised Paediatric Ophthalmology Services 15. Specialised Paediatric Oral and Maxillofacial Surgery Services 16. Specialised Paediatric Orthopaedic Surgery Services 17. Specialised Paediatric Plastic Surgery Services 18. Specialised Paediatric and Perinatal Post Mortem Services 19. Specialised Paediatric Renal Services 20. Specialised Paediatric Respiratory Services 21. Specialised Paediatric Rheumatology Services 22. Specialised Paediatric Surgery Services 23. Specialised Paediatric Urology Services
Source: SSNDS Definition No.23 Specialised Services for Children (3rd Edition)

The critical role of parents in the delivery of paediatric care also distinguishes them from other specialist services.

Identification of specialised paediatric services depends on a number of factors, including diagnosis, severity, other underlying conditions, complications and age.

The complexity and mutual dependency of specialised paediatric services is central to service planning and configuration. A 2008 document agreed by the various Royal Colleges and the Association of Chief Children's Nurses and supported by the Department of Health and the National Specialised Commissioning Group[8] provides a framework for the critical inter-dependencies between the various paediatric specialised services and identifies the core specialised services that should be co-located in a defined specialist paediatric service centre.

Specialised healthcare services for children are provided by specialist, often multi-disciplinary, teams either at the specialist centre itself, or in partnership with local hospitals working through a shared care or outreach arrangement, or in the child's own homes via a specialist outreach team. For specialised as well as non-specialised paediatric services, the objective is to provide care as close to home as possible and with the maximum

[8] *Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies*, agreed by the Royal Colleges of Paediatrics & Child Health, Anaesthetics, Physicians, Surgeons and Nursing and the Association of Chief Children's Nurses and supported by the Department of Health and the National Specialised Commissioning Group.

involvement of the child's parents. Consequently, the development of networks of care, based on shared care arrangements between primary care services, the local hospital and the specialist centre are particularly important for children's specialised services.

There is an overlap between paediatric surgery and all the other surgical specialities involving children. Management of the overlap across these services varies around the country.

Palliative care services are potentially needed for all life-threatening conditions in Children, but are particular important in areas such as critically-ill children on neonatal and paediatric intensive care units, children with cancer, and children with severe congenital heart disease.

2.4 Focus on neonatal services

Given the breadth of specialised service for children, we have taken the decision to focus on the early years of a child's life. This is the area of children's services with the greatest potential to improve quality, innovation, prevention and productivity. Neonatal services account for a large proportion of spending on specialised children's services, in some cases more than 50% as reported at the workshop. Further, many of the transitional issues from neonatal to paediatric care are also relevant to the transition from paediatric to adult services.

Prevalence
In total around 70,000 babies (approximately 10% of all births) each year will be admitted to neonatal care[9]. While approximately 50% of neonatal cases are unexplained, various factors contribute to the risk of neonatal health problems and the need for specialist care (age and lifestyle of mother, pre-term births, multiple births, etc).

Organisation of neonatal services
Neonatal services are based upon SHA populations and organised as 23 managed clinical networks[10] across England. Networks were developed as a result of recommendations from the Department of Health's *Neonatal intensive care services – report of Department of Health Expert Working Group,* 2003. Following this national review of neonatal services, the Department recommended that 'Managed Clinical Networks' "to provide the safest and most effective service for mothers and babies".

Networks ensure that groups of hospitals and neonatal units provide various levels of care locally. Each network is responsible for its own care pathways, guidelines and clinical audit programmes.

Neonatal care as defined by the British Association of Perinatal Medicine (2001) includes three categories of care:

- **Special Care (SC):** Provided for babies who need to have their breathing and heart rate monitored, or be fed through a tube, or be supplied with extra oxygen, or be treated for jaundice. SC services also cover babies who are convalescing from more

[9] Bliss, *The chance of a lifetime?,* 2010
[10] Some are called Perinatal Networks and some Newborn Networks.

specialist treatment before they are able to be discharged (eg, until feeding is established).[11]

- **High Dependency (HD):** Provided for babies who weigh less than1,000g, or need help with their breathing via continuous positive airway pressure (CPAP) or need intravenous feeding, but do not fulfil any of the requirements for IC services.
- **Intensive Care (IC):** Provided for babies who require constant supervision and monitoring and, usually, mechanical ventilation.

Neonatal care services are delivered in three types of neonatal unit:

- **Special Care Units (SCU):** These units provide SC services for their own local population. They also provide, by agreement with their Managed Neonatal Network, some HD services. In addition SCUs provide a stabilisation facility for a baby requiring transfer to a Neonatal Intensive Care Unit for IC or HD and receive transfers from their other Network units for continuing SC. There are 43 SCUs in England[12].
- **Local Neonatal Units (LNU):** These units provide SC and HD services for their own catchment population and transfer babies who require complex care or longer term intensive care to a Neonatal Intensive Care Unit. The majority of babies over 27 weeks gestation will usually receive their care within their LNU. LNUs provide SC and HD services for their own catchment population and may receive transfers for care from other neonatal services in the network if the transfer is within their agreed work pattern. There are 86 LNUs in England.
- **Neonatal Intensive Care Unit (NICU):** These units are sited within Perinatal Centres and provide the whole range of medical neonatal care for their local population and additional care for babies and their families referred from the Managed Neonatal Network. Some Network NICUs in England additionally provide neonatal surgery services and other more specialised treatments. There are 51 NICUs in England, of these 19 units additionally provide neonatal surgery services and other specialised treatment.

Toolkit for High Quality Neonatal Services

The publication of the *Toolkit for High Quality Neonatal Services* towards the end of 2009[13] has raised the agenda and created the opportunity for a more systematic approach to the commissioning and delivery of neonatal services. The toolkit was developed by a national neonatal taskforce. It includes a set of eight principles for high quality neonatal services and a framework to assist commissioners. The principles cover the major areas of activity within the neonatal care pathway and aim to provide standardisation in neonatal care:

- Organisation of neonatal services
- Staffing of neonatal services
- Care of the baby and family experience
- Transfers

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[11] Special care which occurs alongside the mother is often called '**transitional care**' but takes place outside a neonatal unit, in a ward setting. Transitional care is not specifically addressed within the toolkit for high-quality neonatal services.

[12] The numbers of units are derived from the British Association of Perinatal Medicine / National Audit Office census in 2007, reported in the NAO's December 2007 report: *Caring for vulnerable babies: the reorganisation of neonatal services in England*, as quoted in the national definition.

[13] *Toolkit for High Quality Neonatal Services*, Department of Health / NHS (October 2009), available from here

- Professional competence, education and training
- Surgical services
- Clinical governance
- Data requirements

The principles are listed in full in Appendix 4.1.

Recent policy developments
The decision of SW SCG and the Alliance to focus on neonatal services also reflects the fact that separate streams of work are progressing nationally in respect of paediatric cardiac surgery (and subsequently transitions into GUCH services), and paediatric neurosurgery. Meanwhile, there are opportunities to influence best practice at network level for neonatal services as national contracting arrangements are being developed for 2011/12. The Department of Health has said it will mandate in 2011/12 national currencies for neonatal critical care.

NICE issued a quality standard on specialist neonatal care shortly after the workshop.[14] The nine quality standards are listed in Appendix 4.2.

The Department of Health had proposed a significant reduction in the national tariff top-up for specialised services for children in 2011/12. It planned to reduce the top-up from 78% to 25% above tariff prices. However, in December the Secretary of State for Health announced the Department is working on a proposal to set the top-up payment for specialised services for children at 60%. In addition, the Secretary of State said he intended to extend the number of procedures that will attract the top-up payment in 2011-12.

Another important issue is the relationship between neonatal and maternity services, and in particular whether they should be commissioned together by the new NHS Commissioning Board. In its July 2010 White Paper *Equity and Excellence: Liberating the NHS*, the Government proposed that the Board should commission maternity services. However, in the Government's response to feedback on the consultation published in December, it has announced a change in proposed policy.[15] While the Board will directly commission specialist neonatal services, responsibility for commissioning maternity services should sit with GP consortia. The Board will focus on promoting quality improvement and extending choice for pregnant women. The Board will support consortia to work together collaboratively to commission services: consortia will be able to group together, or pool resources with the Board, where this makes most sense.

[14] *Quality standard for specialist neonatal c*are, NICE (October 2010), available from this webpage
[15] *Liberating the NHS: Legislative framework and next steps* (December 2010), available from this webpage

3. Main themes

This section of the report elaborates on each of the key themes and issues from the workshop highlighted in the executive summary:

3.1 Care and treatment

Better matching of provision to need across the various levels of neonatal care.

As set out in the previous section, neonatal care is categorised into patterns of care dependent upon the need for nursing and medical support. Neonatal care and units fall into one of three types.

In 2001, the Department of Health recommended that neonatal services be organised into managed clinical networks, with hospitals working as teams to ensure that babies are cared for in appropriate settings. The neonatal toolkit supported this model of provision (See Appendix 1, Principle 1).

However, one of the main themes of the workshop sessions is that there continues to be scope to improve the matching of babies to the level of care and unit. For example, there are cases of babies kept in specialised care when they could be kept in transitional units.

Commissioners need to manage provision across the various levels of neonatal care, including transfers between them. They need to review the extent of mismatches, and the factors that lie behind such mismatches (for example, financial incentives that encourage units to hold on to babies because of less available funds for transitional care). This should be accompanied by more antenatal information, calibrated by risk, starting to plan for discharge from admission and a common assessment framework with local authorities.

Such reviews may identify scope to reconfigure the composition of services.

3.2 Workforce

The importance of more effective team working.

Workforce issues are a concern of neonatal services, with a shortage of nurses and allied health professionals in particular.

The need for a high quality workforce figures prominently in both the neonatal toolkit and the NICE quality standards. In the toolkit, principle 2 covers the staffing of neonatal services, while principle 5 covers professional competence, education and training. The third NICE quality standard requires that specialist neonatal services have a sufficient, skilled and competent multidisciplinary workforce.

However, one of the main themes of the workshop sessions is that teams work too much in silos, collaborating insufficiently across care pathways. Team members need to spend more time in each other's units. One specific proposal is that new appointments should spend time, including doing shifts, at different units within a network.

3.3 Patients

Greater empowerment of parents, including support for parental care at home.

In all paediatric care, the provision of care needs to encompass both patient and parents. Almost uniquely with neonatal care, the mother needs to be with the baby to optimise its care[16].

The parental experience also figures prominently in the neonatal toolkit and the NICE quality standards. Principle 3 of the toolkit covers care of the baby and family experience. NICE Quality Standard 5 requires that parents "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".

Despite this, one of the main themes of the workshop was that parental support is often insufficient. They sometimes lack the confidence and information to take actions and decisions ("are we allowed?"), with practical implications for challenges such as baby feeding.

Commissioners are developing indicators to monitor and improve patient involvement. For example, East Midlands SCG has introduced a neonatal CQUIN scheme under which parents should have the opportunity to discuss their baby's care with a senior member of the medical team.

According to the NICE Quality Standard, commissioners should ensure that "services use parental feedback on involvement in decision-making and planning and provision of care to inform service improvement of specialist neonatal care". This ought to support to the development of PROMs for specialised neonatal care.

3.4 Innovation

An openness to new models of care, such as the ambulatory care model pioneered in East & North Hertfordshire.

Innovation is the often forgotten 'I' in QIPP. Neonatal, and specialist paediatric services more generally, offer scope for innovative service models that help towards objectives such as delivering more care at home.

An example of innovation presented at the workshop is ambulatory care implemented by *East and North* Hertfordhsire NHS Trust. For E&N Herts, the philosophy behind ambulatory paediatrics is that the child should not be admitted to hospital unless absolutely necessary and as much as possible care should be arranged in their own homes.

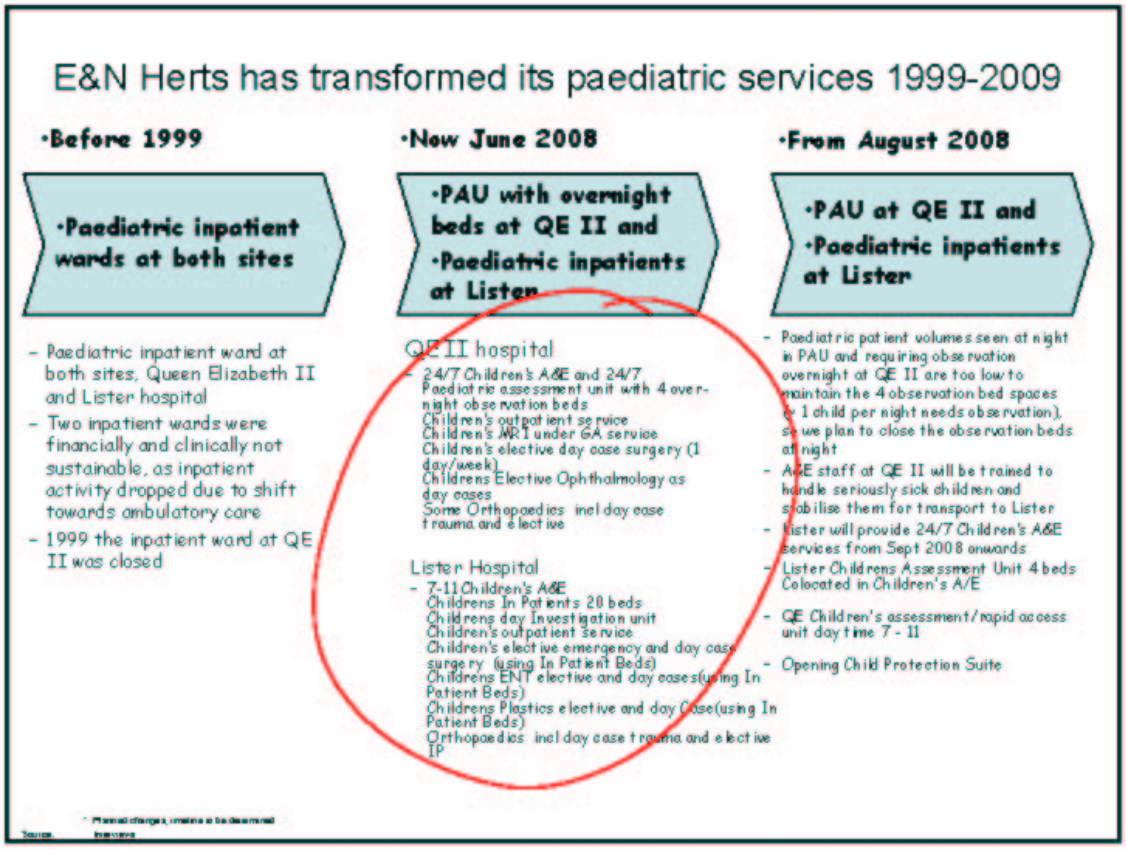
The following slide summarises how E&N Herts has transformed its paediatric services since 1999. Key elements include:

- 24 hours maximum stay in QE II hospital's Paediatric Ambulatory Unit (PAU)
- Transfer of inpatients requiring more than 24 hours stay to Stevenage

[16] POPPY steering group, *Family-centred care in neonatal units: A summary of research and recommendations from the POPPY project*, London: NCT, 2009

- Provision of dedicated ambulance for transfers 2pm-8pm
- 8am early decision rounds on Ambulatory Site
- Development of cross site working
- Requirements of HDU and ICU Care
- Orthopaedic and trauma lists on Ambulatory Service
- New clinical practices for children previously admitted to ward
- Training of SpRs and SHOs especially GP VTS

The changes were driven by both clinical and financial concerns, bringing care closer to children and their parents while reducing its cost.



Current initiatives include the development of a Paediatric Emergency Nurse Practitioner (PENP) Service for protocol led management of minor illnesses. Future plans include the possibility of a nurse-led out of hours PAU.

4. Appendices

4.1 Toolkit for high-quality neonatal services - principles

No.	Principle
1	**Organisation of neonatal services** Neonatal care is organised in managed clinical networks (A) to ensure appropriate expert treatment and provide equity of access to care of the highest standard producing optimal outcomes.
2	**Staffing of neonatal services** An adequate and appropriate workforce with the leadership, skill mix and competencies to provide excellent care at the point of delivery is available in neonatal services, including those providing neonatal surgery. (B)
3	**Care of the baby and family experience** Neonatal care adopts a family-centred philosophy of care that helps families whose baby is in hospital to cope with the stress, anxiety and altered parenting roles that accompany their baby's condition. It puts the physical, psychological and social needs of both the baby and their family at the heart of all care given. Ultimately, family-centred care may enhance attachment between a baby and the family and result in improved long-term outcomes for both.
4	**Transfers** A service is available at all times and to all units within a network, providing safe and effective transfers for newborn babies. This service is additional to the delivery of in-patient care, recognises the importance of family circumstances and provides arrangements to undertake or facilitate transfers in all categories (Appendix J of the toolkit sets out an outline operational specification for a neonatal transfer service) as part of its baseline provision.
5	**Professional competence, education and training** Access to education and training is available to enable members of the multidisciplinary neonatal team to be trained to the level of competence necessary to enable the delivery of high-quality care.
6	**Surgical services** Babies requiring surgical care receive the same level of care, support, resource and specialist input as they would receive in a medical neonatal service.
7	**Clinical governance** A network clinical governance framework monitors the quality of care provided to babies and their families, enables continuous service improvement, encourages clinical excellence and innovation and ensures clear accountability, while maintaining high levels of safety. Research is central to good patient care in neonatology.
8	**Data requirements** High-quality data are required, offering the opportunity to provide accurate information to all clinicians, researchers and patients to improve the outcomes of care.

No.	Principle
Notes: (A) **Managed clinical network** - 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. (B) **Neonatal survery** - Neonatal surgery as defined within this document excludes cardiac and neurosurgery.	
Source: Department of Health, Toolkit for high-quality neonatal services (October 2009)	

4.2 NICE quality standard for specialist neonatal care

NICE launched its new quality standard on specialist neonatal care services shortly after the workshop.

NICE quality standards are produced in collaboration with the NHS and social care professionals, along with their partners and service users. They are the only standards in health and social care that apply nationally in England, and derive from the best available evidence, usually NICE guidance or other sources that have been accredited by NHS Evidence.

NICE quality standards are aimed at patients (including parents in this case) and the public, clinicians, public health practitioners, commissioners, and service providers.

No.	Quality statements
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.
2	Networks, commissioners and providers of specialist neonatal care undertake an annual needs assessment and ensure each network has adequate capacity.
3	Specialist neonatal services have a sufficient, skilled and competent multidisciplinary workforce.
4	Neonatal transfer services provide babies with safe and efficient transfers to and from specialist neonatal care.
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.
6	Mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk.
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.
8	Providers of specialist neonatal services maintain accurate and complete data, and actively participate in national clinical audits and applicable research programmes.
9	Babies receiving specialist neonatal care have their health outcomes monitored.
Source: NICE (October 2010)	