REVIEW

# Establishing neonatal networks: the reality

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Managed clinical networks for neonatal care were established in England from 2004. Their structure and effectiveness varies widely over the country. Changes in medical manpower and the scarcity of neonatal nurses make the move towards networks urgent, but there is little evidence of a coordinated approach to improving capacity in the tertiary centres, who will have to absorb the activity that follows reconfiguration. Changes in the governance of hospitals, NHS authority boundaries and in commissioning specialist services, with the drive towards reducing health costs, places the process at some considerable risk. Despite these challenges, the development of coordinated clinical networks will be an important force in improving outcome for very preterm babies in the UK. The development of some form of national coordination of network activities and greater sharing of good practice would enhance the value of the managed clinical neonatal networks.

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Managed clinical networks are defined as linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner to ensure equitable provision of high-quality clinically effective services, unconstrained by existing professional and Health Board boundaries.[1] Such managed clinical networks are one way of ensuring that the various health-based organisations within a locality can work together to improve the service provided to patients and their relatives within the focus of the target condition. The focus should move from the structures within which care is provided to the provision of predictable, equitable and appropriate seamless care for the patient across a range of interdisciplinary and multidisciplinary processes.

Specialty-specific managed clinical networks have been around in the UK for sometime. In terms of cancer, the premise was to drive forward a government agenda, and the process was well funded and centrally organised. The measurable outcomes were in terms of both access and clinical outcomes. The intention was to produce access to an appropriate level of professional expertise, whether from nurses, doctors or other health professionals, and thus a consistent quality of care.[2] This network concept has been rolled out to other areas of clinical practice including critical care disciplines, diabetes and cardiology. In adult and paediatric intensive care, a further premise was to reduce public anxiety and maximise local capacity so that long transfers were avoided. Significant central funding was directed at these services to establish the networks and to change practice. But even when the rationale and mandate are clear, developing a network may still be considered "challenging".[3]

Other drivers are important in the progression of networking.

- Concerns that across the UK there are serious inequalities in health provision in different areas.[4]
- The recognition that health professionals performing specialist tasks need to have appropriate training, expertise and ongoing professional development.[5]
- Changes in medical staffing and training have placed increasing pressure in the provision of 24 hour specialist care; the European Working Time Directive and Modernising Medical Careers mean that trainees spend less time in neonatal intensive care and therefore their level of expertise is less, training periods shorter, and consultant hours have reduced.
- Nursing recruitment into intensive care areas has proved difficult, and in many areas of the country there is a dependency on temporary staff to fill in common gaps in provision; furthermore the cycle of recruitment, investment in training, and then failure to retain qualified-in-specialty neonatal nurses is an expensive and exhausting process for many tertiary units.
- The introduction of the new consultant contract in 2004 invariably showed that consultants providing neonatal care were working in excess of 48 hours a week, increasing the need to reconsider service delivery models around networks.

Other pressures have been acting within neonatal care to encourage networking. The UK has a higher rate of prematurity than many of our European neighbours,[6] and traditionally most district hospitals have carried out intensive care for babies born in their maternity services, using regional referral centres as "overflow" or for babies who require neonatal surgery or more complex care. As neonatal intensive care has developed in terms of intensity and complexity, there have been major improvements in survival and neonatal morbidity, which increase pressure on cot capacity. Over the past 10 years, this has resulted in the need for one extra cot per year for the Trent Region of the UK simply to account for improvements in survival and length of stay for babies less than 26 weeks of gestation at birth.[7] The lack of any strategic investment in neonatal services until recently effectively means that the capacity of tertiary services has been steadily eroded over time.

In 2001 the British Association of Perinatal Medicine updated their 1996 Standards for Hospitals providing Neonatal Intensive Care. This included a revision of the definitions of care levels, a recommendation that hospitals work together in networks, and that care for the smallest and sickest babies be concentrated in larger centres.[8] Because of ongoing concerns about the common transfer of babies and pregnant women inappropriately in an unplanned fashion and over long distances,[9] the Department of Health convened a working group, and a report was published as a consultation document by the Secretary of State.[10] The instruction was given to Strategic Health Authorities to establish networks of neonatal care, and a small amount of money (approximately £20 m per annum recurrently from 2006) was provided to develop neonatal care, including the development of neonatal networks.

## HOW WERE NETWORKS ESTABLISHED?

The financial support for this development was divided on a per capita basis and devolved to local commissioners. In some areas, this was reclaimed centrally by specialist commissioning services and put to work within the specialty. In others, the funds were retained by the local Primary Care Trusts and only reluctantly given up after due process. Thus in some areas of the UK, the process was facilitated by strong specialist commissioning groups with a responsibility for strategic development, and in others the process became mired within local funding difficulties which had to be disentangled before the network could evolve. Examples of structures of networks and how they vary was recently undertaken by BLISS.[11] [12] This shows significant differences in the structure of networks. As yet, roles and responsibilities have not been shared but may be as variable as the structure.

One of the first tasks given to networks was to agree designation for services along the lines set out in the Department of Health document as level 1 (special care), level 2 (high-dependency and short-term intensive care) and level 3 (full neonatal intensive care unit/tertiary) (table 1). This was inherently divisive because of the lack of engagement, particularly in local district hospitals, which had been forced to deliver a wide range of intensive care services because of a lack of capacity in the tertiary centres (local services that they were often rightly proud of), and the prevailing view, unique to the UK, that the advantage in the centralisation of neonatal critical care seen in other countries[13–19] did not apply to us because it had not been confirmed in a UK population.[20]

Despite the flexibility inherent in the Department of Health report, which has been incorporated into the Children's and Maternity Services National Service Framework (NSF) published in 2004[21] and as such is government policy, there was and is a degree of rejection of the model in several areas. The report does not dictate exactly what should be done, but attempts to guide networks as to the direction of travel. The single biggest area of conflict is in the suggestion that moderate-sized local hospitals (often 3000–4000 births), which had been providing full intensive care services for some time, should now stop doing so for the extremely preterm population. There appears to be a reluctance to drive this standard from the centre, leaving individual networks to work out how to work towards it. There is now evidence that the combined "intensive care" capacity of district hospitals may be greater than that of the tertiary centres,[22] but financially and logistically it is simply not possible to support the development of full intensive care services at these sites. Without appropriate investment in the near future, neither will there be the capacity within network tertiary centres in most areas to accept the work currently done at these designated "level 2" units and thus it will be impossible to meet this NSF standard in many areas.

Furthermore there is also a perception that "all" intensive care work must be taken out of a hospital designated "level 2", which is not the case. It was recognised that skills must be maintained and that there would be a gestational limit below which there would be mandatory transfer out, but that "level 2" hospitals would continue to provide significant amounts of short-term intensive care for babies born at or above this gestational age limit and liaise with their tertiary unit over the duration of this. Hence a unit delivering 4000 babies a year would still require significant facilities and experience to continue to deliver this care to a high standard.

The focus on days of intensive care as a measure of a neonatal service's activity rather than numbers of babies receiving intensive care may have driven this problem. Many level 2 units have a small number of intensive care spaces (usually less than four), which are commonly occupied by babies who survive and need long-term ventilatory support. The consequence is that they block capacity for the larger numbers of relatively more mature babies needing short-term ventilation, thereby reducing the exposure to managing the acute ventilatory requirements for these babies. It is the perceived "excitement" of managing the early phase of care that many paediatricians feel they would lose if a gestational limit was applied, whereas, we believe, the converse may be the case.

## DO NEONATAL NETWORKS HAVE A ROLE?

### The contract with the pregnant woman

Central to the philosophy of the Department of Health report was the concept of the nominal "contract" that health providers should make with the woman who is pregnant. The "majority of care for pregnant and newly delivered mothers and their babies should be delivered as close to their homes as possible, and, where possible, in a setting of their and their partner's choice."[10] Women should also have an explicit plan as to what would happen if a problem arose during the pregnancy that required specialist help and know where that help would be provided. Where they or their child needed care that was available only outside their local setting, arrangements would be made for shared care, or their return to local care as soon as possible. It is within this "contract" that networks should operate to provide the highest quality care. The major themes for network activity could thus be: delivering the contract with the pregnant woman; clinical governance; improving outcomes;

**Table 1** Pragmatic definitions of different designations of neonatal services

| | |
|---|---|
| Level 3 | One staffed by consultants, all with specialist neonatal training, and where all medical staff, when clinically responsible for the neonatal service, have no other commitments |
| Level 2 | One staffed by consultants and resident experienced doctors who also cover an adjacent children's service but with one doctor/advanced nurse practitioner available for the service at all times without other commitments |
| Level 1 | One that plans to provide neither intensive nor high-dependency neonatal care except in an emergency |

**Table 2** Roles for neonatal networks

- Delivering the contract with the pregnant woman
  - Coordination of care within known group of hospitals
  - Information collection and collation
  - Maintenance of local services
  - Ensuring equality of access
  - Delivering the appropriate services in the right place, as close to home as feasible
- Clinical governance
  - Guidelines
  - Audit
  - Education
  - Training
- Improving outcomes
  - Maintaining and improving quality standards
  - Providing advice on service redesign
  - Developing care pathways
  - Benchmarking
- Commissioning roles
  - Setting standards
  - Monitoring outcomes
  - Agreeing strategy
  - Supporting investment

support for commissioners. These are expanded further in table 2.

One important issue raised in the Secretary of State's introductory letter was that the impact of the change in the way the small proportion of babies who require intensive care are looked after should not alter the configuration of maternity services, allowing the majority of care still to be delivered close to the woman's home.[10] Although this is true for the vast majority of care episodes, there are significant implications for local fetal and maternal medicine services, where interruption and transfer of their care may be necessary because the delivery will be at another hospital. Thus networks should really comprise "perinatal" rather than simply "neonatal" services. Evidence of this happening nationally remains patchy, and, in truth, it is difficult to deliver, as fetal medicine and neonatal intensive care units may not be co-terminus. It is necessary to draw the distinction between maternity networks (where the majority of care episodes are for "well" women and babies) and critical care networks (where there are non-routine clinical problems to be managed). We see "perinatal networks" as dealing with situations where the mother or the fetus/baby requires specialist care.

## Coordination of activity

Within each designated network area, the Neonatal Network facilitates the coordination of care for that group of hospitals. The goal should be to achieve an appropriate level of care in the right place. This is not simply the development of large tertiary services but the delivery of neonatal care across the network, so that there is equality of access and standards of care for all sick or preterm newborn babies. In addition to supporting units delivering intensive care for more mature babies, the network should work closely with local services to ensure that babies have cots to return to when their period of tertiary care is complete; preadmission and discharge care pathways in non-tertiary hospitals may require redesign to keep cots available for continuing post-intensive care to optimise the use of the network intensive care facility.

Key to the delivery of this coordination role is the availability of robust information on activity and outcomes. Network-wide information technology must be available to support monitoring of activity. Slowly (and at different speeds) this is being resolved. In some areas there are established data coordination systems, but in others there remain disparate or absent data systems which require prioritisation and development. The provision of a basic dataset[23] and its more recent upgrade (www.bapm.org) facilitates the development of such systems, and the approaching new care-day-based reimbursement system will drive this forward.

The absence of nationally developed clinical guidelines has meant that hospitals have developed their own in isolation, often reflecting historical practice and personal preference. The inception of the Neonatal Network means that network wide guidance can be developed to mesh the care delivered across the network so that the clinical care process becomes seamless. Within the Trent and Yorkshire Networks, we have prioritised clinical guidelines covering neonatal transfer, early care for the very preterm baby, and preoperative care as important areas where working together can be achieved.[24]

## Quality standards

Published national standards provide important foundation standards for the structure, organisation and monitoring of neonatal intensive care in the UK.[8] Neonatal Networks have a role in the maintenance of these standards but also in developing local targets for access and outcomes, monitoring the effect of local service redesign, and in the development of clinical pathways and care bundles which provide auditable quality measures of care. In these areas, networks should work with commissioners to establish monitoring and standards through contract design and implementation.

Maintaining the goal of providing care close to home with appropriate level of support requires complex planning and negotiation with acute hospitals, community services and networks. The development of a nurse consultant post in neonatal surgery in Yorkshire provided the opportunity for babies managed in central surgical units to be returned closer to home for on-going care. This required the development of appropriate guidelines for surgical conditions and a clinical decision-making guide for all levels of staff from surgeon to nursing. The role of the nurse consultant has been to provide education, training and advice at all stages in the care from the central surgical unit to the local hospital and to home. As a result of this service redesign, in excess of 300 bed days has been released from the central unit (in 6 months) freeing up capacity (unpublished). In addition, it has increased the complexity of care delivered in the local units but maintained standards. Auditable standards have been developed showing no change in complications/problems, and questionnaire-based processes have shown full support from parents and staff.

In the UK, there are few opportunities to benchmark unit performance. At a regional level, some areas provide comparative figures for simple mortality, adjusted mortality and basic morbidity. Areas of nursing practice may be benchmarked through local or national schemes. Some units in the UK contribute to the US-based international Vermont Oxford Network. A national neonatal audit is currently being piloted in England (www.ncap.nhs.uk), which builds on the results of previous national audit.[25] This will answer eight questions about the process of care (were antenatal steroids and surfactant given appropriately, was blood pressure measured, were babies managed in the normal clinical pathway, etc?) and one concerning outcome (are rates of normal survival at 2 years comparable in similar babies from similar units?). The collection of quality information on this scale will be a challenge in the absence of supporting routine data systems.

### Clinical governance

Many of the roles assumed by and assigned to Neonatal Networks overlap with local Trust Clinical Governance processes where the chain of responsibility is clear, in contrast with the authority of a Neonatal Network, which is not. Networks have an advisory role and are a useful resource for Trusts in notifying and supporting clinical governance systems. An example of good practice in this area is the sharing of ''Serious Untoward Incidents'' across the Yorkshire Neonatal Network. This lack of authority around clinical governance has weakened the ability of networks to develop standards at the pace many would be hoping to achieve. Networks should use their advisory role to its full effect where it finds evidence of lower standards of care.

### Commissioning roles

Specialist commissioning is undergoing reorganisation along with the changes to the Strategic Health Authorities in the UK.[26] Commissioning specialist services is a complex task within which the Neonatal Network will advise the commissioner on the inclusion of quality standards in the contracts. Neonatal Networks have important roles in monitoring the performance on a network basis of individual units against contract and for identifying strategic investment points so that resources can be targeted wisely. There is some debate as to whether these roles are rightly the responsibility of the Neonatal Network and whether there should be a clearer division between commissioning and provision of service. However, as an overarching organisation, a Neonatal Network should be structured to do this with some degree of separation of roles within network managerial arrangements. This enhances clinician representation in these specialist areas and allows strategic, as opposed to piecemeal, development of services.

## WHAT ARE THE BARRIERS TO SUCCESS FOR NETWORKS?

There can be few who disagree with the underlying principle behind networks: that neonatal services should work together in a coordinated and facilitative manner to improve the outcome for the sick or very preterm baby. However, within the current NHS structures there are several constraints that work against the implementation of this principle.

Firstly, what authority does the network have to effect change? Where the network is formally convened under the aegis of a commissioning body, authority may be effected through the commissioning and contracting process, which is a powerful tool. Where the format of the network is less clear, for example more of a clinical provider network, there is a tension between the relatively independent NHS Trusts and the work of the network—for example, a Trust is free to pursue a course of action contrary to the network advice if they decide that this is appropriate against a local risk assessment. It does therefore become much more important that a network has a clear commissioner basis to its construction and seeks to define its role within the new Strategic Health Authority structures.

Secondly, the concept that reconfiguring the neonatal services in a region can be achieved without affecting maternity care poses difficulties. Obstetrics and particularly fetal medicine are at a stage of specialisation much as neonatal intensive care was 10 years ago. Relatively unfettered and to some extent encouraged by a devolved neonatal intensive care service, fetal medicine has grown as a specialty in many local hospitals, resulting in the delivery of babies with more complex problems in services that have not the infrastructure to support such activity. Fetal medicine does have an important role alongside district neonatal services, but a small number of women—with fetal abnormality or threatened extremely preterm labour—will need transfer for delivery within the network structure. This poses finite limits on care and meets resentment. Local services are an attractive public platform that can work against the delivery of good regionalised care and good outcomes. Developing a robust network of fetal medicine specialists alongside the neonatal service is of crucial importance, as the workload goes hand-in-hand. We would support not simply the renaming but the reconfiguration of Neonatal Networks to engage feto-maternal medicine in true ''Perinatal'' Networks.

Furthermore there are significant tensions in the role of tertiary hospitals in their responsibility as local maternity services and in their delivery suite capacity, which may need re-evaluation as the number of in utero transfers increases.

Surgical care poses yet further constraints in that in many cities, because of historical placement of services, the neonatal surgical service is sited remotely from the regional neonatal service against recommendations.[8 10] This brings problems of transfer for surgery, of postoperative care, of the care of the mother with obstetric needs, and of a further change in staff at a point when the child is critically ill. Furthermore, the experience of the staff providing what may be often complex intensive care for particularly the very preterm child may be considerably less than that present on a formal neonatal intensive care unit.

Parental and public inclusion in network decision-making is essential. However, identifying parents and equipping them with skills to ensure that they play a substantive and important role in the network is challenging. BLISS, the premature baby charity, is developing training and support packages to assist the proper development of this role which promises to deliver a sustainable and valuable role for parents/the public in developing network activity.

By the very nature of the structure of Neonatal Networks, charges of conflict of interest may be voiced. Neonatal leads are commonly, but not exclusively, drawn from tertiary specialist doctors and nurses who have a vested interest in delivering high-quality neonatal care, which is to some extent centralised for the sickest and most vulnerable. Attempts to designate units de novo as part of the initial work of networks in particular has led to disenchantment of some local neonatal specialists whose service has been designated as ''level 2''. The need for robust designation processes with appropriate people taking decisions at an appropriate level was clear from the outset and has by and large been achieved. The use of assessment tools based on published standards has helped to make this process transparent.

## WHAT DOES THE FUTURE HOLD FOR NEONATAL NETWORKS?

### Reorganisation

The NHS is constantly facing new challenges,[27] and just as Neonatal Networks are becoming established it has become necessary to interact with new structures and new boundaries. The new Strategic Health Authorities on which networks are based have different boundaries from their predecessors, and specialist commissioning arrangements are evolving as alluded to above. Network teams must interact early with their new Strategic Health Authority representatives in order to move the

**Table 3** Roles for networks within NHS management structures

| Provider roles | Commissioner roles |
|---|---|
| ● Maintaining and improving standards<br>● Data collection and collation<br>● Defining clinical pathways<br>● Auditing against standards<br>● Education and training<br>● Purchasing power | ● Setting standards<br>● Monitoring outcomes<br>● Agreeing strategy<br>● Supporting investment |

issue of networks to centre ground. Clarity over the roles of each network (table 3) and the relationship of the network to specialist commissioners need to be established. One commissioner's view is that networks are simply doing the job of a good commissioner!

### Payment by Results

The basis on which neonatal care is to be funded is likewise to be changed, and the proposals under Payment by Results have recognised the complexity of neonatal intensive care. Funding has been agreed in principle based on care-days stratified by category of care into routine care plus intensive, high-dependency, special care with and without mother. Expensive items are likely to be reimbursed outside this scheme, and a notional price for a ''transport'' is being developed. Two issues flow from this and are critical to its success. Firstly, the care level needs to be transparent and verifiable, so a system to calculate this is required, and, secondly, it can only work if commissioners write good quality neonatal contracts with verifiable quality markers which are based around published standards. Trusts must allow transparent funding streams to ensure that the money follows the patient, and care must be taken that hospitals work within an agreed configuration framework within the network. Early indicators are that it could be a very sensible system, but the quantum of price is yet to be set, and on that will hang the success or failure of the system, depending on whether it is possible to meet quality standards of the NSF within the tariff set.

### Foundation Trusts

The role of Foundation status for Trusts likewise requires some time to settle, as the measure of independence that accompanies this must not be allowed to work against the strategic development of Neonatal Network-led care, and the use of Payment by Results to generate income must be carefully monitored.

Other networks are considering their own future within any locality. In particular, there is much to learn from the success of adult and paediatric critical care practice, and the problems they face are similar to those faced by Neonatal Networks. Within any locality, there is value in co-location and close cooperation between critical care networks and, indeed, with the evolving children's services networks, which function more on a provider basis.

There is no national coordination of the work of Neonatal Networks and as such there is a danger of duplicated effort. Particularly as we move into the new structure of specialist commissioning, there is a need to share experience and process. A national organisation would be welcome.

## MEASURING SUCCESS

How will we know whether networks have been successful in their role? It would be attractive to think that we are likely to show a reduction in neonatal mortality and other morbidity measures. Indeed the establishment of national databases with ongoing nationally collated data to be able to demonstrate this would be a noble goal for neonatology generally.

In essence, the provision of a workable system for neonatal care—equality of access for all, appropriate capacity and staffing for intensive care, a reduction in inappropriate transfers and networks that are owned by their constituent units—must be the ultimate short-term goal of this process.

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# IMAGE OF THE MONTH

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## A hypothyroid neonate with a lingual tumour

We report a healthy baby boy, born after an uneventful pregnancy at 40 weeks gestation, birth weight 3420 g, Apgar 9–10–10. On examination the baby had a lingual mass anteriorly situated in the midline, 5×5×5 mm. It was not painful but it had a hard consistency. There were no respiratory or feeding problems. However, screening for congenital hypothyroidism was positive.

He was treated with levothyroxine. Further investigation using technetium 99m scanning and ultrasound suggested dystrophic cervical thyroid tissue. Histopathological and immunohistochemical studies showed no thyroid tissue in the tumour. This was to be expected owing to the fact that ectopic thyroid tissue on the tongue is almost always found posteriorly. Further histological evaluation showed striated vascular tissue and smooth muscle fibres. Leiomyomateus hamartoma was diagnosed (fig 1).

Hamartomas are malformations of histologically normal cells in an abnormal structure. Hamartomas of the tongue in neonates are extremely rare, mostly located posterior to the midline and often of vascular origin. As a rule, recurrences after resection are rarely seen.

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**Figure 1** Baby with hamartoma of the tongue. Parental consent was obtained to publish this figure.

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