

Caring for Vulnerable Babies: The reorganisation of neonatal services in England

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- 1 Most babies are born healthy requiring little or no medical intervention. Every year, however, around ten per cent of babies are born prematurely or suffer from an illness or condition which requires care ranging in complexity, from a local special care baby unit to a highly specialised neonatal intensive care department (Figure 1). Prematurity and illness in newborn babies are associated with a complex range of factors, including social deprivation, ethnicity and maternal age, assisted conception and lifestyle factors. Babies can also require care arising from complications of pregnancy and delivery, from medical disorders such as infection or metabolic disorders or when surgical or other treatment is required for congenital anomalies.
- 2 Over the last 20 years, neonatal services have undergone substantial organisational and technological changes whilst remaining a challenging and necessarily innovative area of medicine. Specialised training of doctors and nurses underpinned by technological advances has led to greater numbers of very small babies being born alive and surviving. Year on year increases in birth rates and improvements in survival rates have placed increasing pressure on the capacity of neonatal services and led to some instances of babies being transferred long distances to receive definitive care.
- 3 In 2001 the Department of Health (the Department) commissioned an expert working group to review neonatal intensive care services. The resulting report, published as a consultation document in April 2003, proposed the reorganisation of neonatal care into managed clinical networks so that units in each network would provide virtually all the care required by mothers and babies without the need for long-distance transfers. This followed evidence from other countries that networked models of intensive neonatal care produced the best outcomes for babies.¹⁰

- 4 The Department endorsed the report's recommendations and at the same time announced an additional £72 million between 2003-04 and 2005-06 to help implement the recommendations. The distribution of these additional funds was weighted by incidence of low birth weight. In 2006-07 some £420 million was spent on running neonatal units.^a
- There are important ethical issues surrounding neonatal care, such as the gestational age at which it is appropriate to treat extremely premature babies and the long term impacts of disability. These issues were addressed in the Nuffield Council on Bioethics 2006 report. Our report does not comment on these decisions nor does it examine issues aimed at reducing the risks of premature and low birth weight babies, for which there are a number of NHS and cross-Government initiatives. Rather, our focus is on how well the introduction of networks has helped the service respond to the increasing demand for neonatal care. Full details of our methodology are at Appendix 1.

Findings

6 There is widespread support for neonatal services to be delivered through managed clinical networks, but these networks have evolved at different rates.

Most neonatal units in England organised themselves into formal networks linked by supervisory management structures, although there has recently been some shifting of network boundaries, including one merger (Appendix 2). As specific arrangements are determined locally, variations exist in network budgets, stakeholder representation and the roles networks have assumed. All networks have developed their own neonatal care pathways, guidelines and clinical audit programmes. However, there has been less progress in influencing

a This covers the costs of special, high dependency and intensive medical care provided in neonatal units plus surgery where it is provided on the same site, but excludes costs of babies treated in other specialist surgical units.

commissioners and Trusts to re-designate units according to the care they are able to provide, which was one of the key recommendations of the 2003 Review.

- 7 Most networks have made progress in reducing long-distance transfers, but only half provide specialist transport services 24 hours a day, seven days a week. Neonatal transport is an essential element of networked neonatal care including transfers to, between and back from units. Networks generally deploy some form of specialist transport service during day time working hours, with half providing a 24-hour, seven day-a-week transport service. Seventeen out of 23 networks are now meeting the target of treating 95 per cent of babies within the network. However, few transport services have separate staffing arrangements from the clinical inpatient service. As a result, staff often have to leave their unit to accompany a baby on a transfer, putting pressure on remaining staff.
- Evidence of outcomes, other than the traditional indicator of mortality rates, is sparse and these rates show unexplained variations. Whilst management information is improving, it is not yet strong enough to provide evidence of improvements in quality of care. The neonatal mortality rate for England was 3.7 (deaths per 1,000 live births) in 2003, 3.4 in 2004 and 3.5 in 2005, which is within a similar range of other comparable countries. This national figure however masks wide variation at the network level. We focussed on neonatal mortality rates at network level in recognition that at unit level a complex combination of factors can affect the mortality rate; and that we would expect some variations to be smoothed out at the network level. In 2005 Midlands South (South West Midlands) had the highest rate (4.8 per 1,000) and Surrey and Sussex the lowest rate (1.8 per 1,000). Whilst this may be due to the demographics of the population covered by the network, differences in service provision may also be a factor.
- 9 Networks have improved communication and coordination between units and now have better, more consistent information on performance. All networks have agreed their own protocols, standards and pathways of care. The Healthcare Commission, supported by the Department has funded a Neonatal Audit Programme minimum dataset. Seventy per cent of units (n=153) now use a neonatal net electronic patient record, making information easier to record and creating opportunities to evaluate. Networks have also supported the development

of regional data sets, enabling analysis and benchmarking of data. However, there is a high level of duplication of data collection and a need for consolidation and harmonisation.

- undermine the effectiveness and efficiency of neonatal care. One of the key indicators of the capacity of a unit is the frequency with which it has to close to new admissions (each unit had closed to new admissions an average of 52 times during 2006-07 due mainly to either lack of cots or shortages of nursing staff (n=122)). Fifty-eight units (33 per cent) operated above the British Association of Perinatal Medicine (BAPM)^b guideline of 70 per cent cot occupancy and three units above 100 per cent.^c Although there has been an increase in the numbers of intensive and high dependency cots, most special care units had to care for babies needing these higher levels of care.
- 11 A key reason for problems with capacity is nursing shortages. Most units had an adequate level of medical staffing and were in line with the BAPM 2001 medical staffing guidelines. The situation with nursing is much more critical with significant shortages of trained nurses across the country and wide regional variations in vacancies (Appendix 3). Only the guideline for special care, one nurse to four babies, is being met. Half of all units met the standard for high dependency care but only 24 per cent did so for intensive care (n=151).^d
- 12 Parents are mostly very happy with the specialist care and expertise their babies receive, but they also have needs which are currently not always met. Parents' views of the service are important given that babies cannot speak for themselves and the former are extremely appreciative of the care their babies receive. However, their needs are often overlooked. Parents have consistently suggested a need for improvements in support for breastfeeding, information about their babies' care, communication with medical staff, car parking and accommodation to enable them to stay with their babies.
- 13 The separation of commissioning for different levels of care causes difficulties in planning services. Special care is commissioned by Primary Care Trusts (PCTs) and high dependency and intensive care are commissioned by the ten Specialised Commissioning Groups, despite the tendency of babies to move rapidly between these levels of care. In addition, there is no

b The British Association of Perinatal Medicine is a professional organisation, which aims to improve the standard of perinatal care in the British Isles. BAPM's Standards for Hospitals Providing Neonatal Intensive and High Dependency Care (Second Edition) was published in December 2001. They are professional guidelines, endorsed by the Council of the Royal College of Paediatrics and Child Health and the Trustees of BLISS (the national charity of the newborn) and are not mandatory standards.

c See paragraph 3.4 for more details on how occupancy rates were calculated.

d Unit staffing can vary from shift to shift. Vacancy levels are against establishment.

formal link between the commissioning of maternity and neonatal services, despite the fact that the former is a key driver of demand for the latter.

14 The costs of the service are not fully understood and there is a mismatch between costs and charges.

Data provided by units suggest wide variations within and between the different types of unit, from one unit with an operating deficit of £2.6 million to one with an operating surplus of £4.9 million. Charges for neonatal care do not necessarily reflect costs and financial management at the unit level needs to be improved. The future introduction of Payment by Results could bring positive benefits for neonatal services, although there are concerns about the practicalities of its introduction.

Overall conclusion

15 The reorganisation of care into neonatal networks has improved the coordination and consistency of services, pointing to increased effectiveness. There are however still serious capacity and staffing problems and a lack of clear data on outcomes. In addition, the variable state of financial management makes it difficult to judge the economy and efficiency of the service. We are therefore unable to say whether or not networks have improved the overall value for money of the service. Nonetheless the majority of parents are grateful for the care their babies receive. Given the rising demand for the service and the constraints within the system, parents' views are an important indicator of achievement, but the lack of robust evidence on outcomes makes it difficult to reach an objective view of the quality of the service.

Recommendations

- 16 Reducing disparities in mortality rates cannot be addressed through improved neonatal services alone. Reducing the prevalence of premature and low birth weight babies requires a range of coordinated NHS, public health and cross government initiatives. Many of these, such as programmes to reduce teenage pregnancies and smoking, are already in train. Once a baby is born, however, neonatal services should provide high quality, safe care in an appropriate setting, keeping transfers of the baby to a minimum. The following recommendations are focused to that end.
- a Issue: The 2003 Review did not specify how the performance of networks in meeting the needs and outcomes of neonates should be managed. It also occurred prior to the recent reconfiguration of Strategic Health Authorities and Primary Care Trusts.

- Strategic Health Authorities and commissioners should define the performance management arrangements which will monitor the outcomes of the networks drawing on our evaluations of the current situation as illustrated in Appendices 2 and 3.
- **b** Issue: Neonatal services are part of a continuum of care which starts with maternity services but they are at present commissioned and planned separately rather than as part of a whole systems approach. There is a need for:
 - Targeted research, whether commissioned by the Department or by other appropriate funders such as the relevant professional bodies. This needs to be aimed at reducing the demand for neonatal care through improved understanding and prevention of the trigger factors which are associated with preterm birth, low birth weight and sickness in newborns.
 - Commissioners and networks to coordinate the commissioning of neonatal and maternity services. This should include undertaking strategic needs assessments of the local population, taking standards set by professional bodies into account and addressing the blockages in networks which prevent efficient in-utero transfers.
- c Issue: At the moment special care is commissioned separately from high dependency and intensive care. There is consensus that they should be commissioned together and in some networks commissioners have moved to this arrangement. Networks, commissioners and Strategic Health Authorities should work together to commission care pathways across all three levels of care including transport to enable capacity to be planned and managed effectively. Lessons from Kent and Medway and other networks already implementing this approach should be evaluated by the national group of specialist commissioners and neonatal network managers and adopted or adapted as necessary.
- d Issue: Although three quarters of networks have reviewed the designation^e of all or most of their units, re-designation has not been implemented in full for a variety of reasons. Without meaningful re-designation processes, networks may find it difficult to ensure they have appropriate capacity to meet demand safely. Using evidence from professional bodies, commissioners should drive re-designation to enable capacity to match the needs of their population and that babies are being cared for in
- e This refers to the type and intensity of care a unit can provide and is outlined further in paragraphs 1.14-1.16 and in figures 4 and 5.

- settings with appropriate staffing levels and skills. In doing this, they will need the support of Strategic Health Authorities and full cooperation of NHS and Foundation Trusts in each network.
- e Issue: Progress in improving the quality of management information at unit, network and national levels is slow. The availability of this information is vital for establishing the efficiency and effectiveness of the service, particularly in calculating the long-term impacts of different types of care. All neonatal units should, as a priority, contribute fully to the Neonatal Audit Programme minimum dataset, regardless of which system they use to gather data. The neonatal network managers group should work with units and the Department to reduce duplication of data collection.
- f Issue. Transport arrangements are still not optimised in terms of responsiveness or cost-effectiveness and have developed in a piecemeal fashion. As a result, delays are still occurring and unit staff are being diverted to accompany transfers. Networks and Strategic Health Authorities should examine the relative cost-effectiveness of the different transport arrangements currently in place and look to join up either with neighbouring networks or with paediatric intensive care transport services if necessary to achieve the optimum geographic coverage.
- g Issue: On average each neonatal unit in England is currently carrying three whole-time equivalent nurse vacancies and the proportion of vacancies increases as the intensity of care provided increases. Very few units are meeting the recommended nurse staffing guidelines. NHS and Foundation Trusts should develop a targeted action plan to address neonatal nurse staffing shortages. In addition to addressing staffing levels as part of the commissioning process, solutions may be found by working with NHS Employers to address recruitment or retention issues and with Strategic Health Authorities to commission more neonatal nurse training courses.

- h Issue: There are variations in the way Trusts calculate costs and charges for neonatal care, making it difficult for commissioners to allocate resources effectively. NHS and Foundation Trusts should improve the completeness and accuracy of financial management data on neonatal activity, by using developments such as patient-level costing and service-line reporting, and ensure that overheads are apportioned in a consistent manner.
- i Issue: The implementation of Payment by Results (PbR) for neonatal services is due to be considered by the PbR Children's Services Clinical Working Group alongside the new neonatal dataset. There are widespread concerns that not enough work has yet been done to create a set of tariffs which capture the full costs of neonatal care. We have also identified considerable variation in the costs and charges as they are currently understood by Trusts. In determining a future tariff or tariffs for neonatal services, the Department of Health advised by the Payment by Results Working Group needs to take into account the findings of this report, in particular our findings on the wide range of Trusts' costs and charges, and ensure that transport costs are included.