Perinatal and neonatal mortality in the advent of the neonatal network

Infant mortality is highest during the neonatal period. The provision of medical care for low birth weight and premature babies is challenging. Neonatal networks aim to improve outcome, optimize efficiency and increase the quality of care for these infants.

The neonatal period has one of the highest mortality rates of any period of life. Worldwide over 4 million babies die every year in the first 4 weeks of life and 70% of all infant mortality occurs during this time (World Health Organization, 2007). Perinatal mortality is the death of a fetus or newborn during the perinatal period, which commences at 24 weeks' gestation and ends at 6 completed days from the time of birth. Neonatal mortality is the death of a live born baby from the time of birth but before 28 completed days of life. In developed countries the most common cause of neonatal mortality is prematurity. Congenital abnormalities and infection also contribute. In 2007, 74% of neonatal deaths in England, Wales and Northern Ireland were preterm infants born at less than 37 weeks' gestation.

Babies born with a low birth weight (less than 2500 g) and very low birth weight (less than 1500 g) have an increased risk of neonatal mortality compared with babies of birth weight greater than 2500 g (Confidential Enquiry into Maternal and Child Health, 2009). In the UK, the neonatal mortality rate has been steadily declining and is currently 3.3 per 1000 live births (Confidential Enquiry into Maternal and Child Health, 2009). The overall birth rate in the UK has been rising since 2001 and the Office for National Statistics confirms that this trend is likely to continue.

The incidence of extremely preterm birth (less than 28 weeks' completed gestational age) is increasing in the UK (Yeaney et al, 2009). The UK has a higher rate of prematurity than most of its European counterparts (Field et al, 2002). Survival of preterm or low birth weight babies has improved significantly. Infants born in the UK at 24 and 25 weeks' gestation have survival rates of 43.3% and 59.2% respectively at 28 days of age (Costeloe et al, 2000). This improvement in outcome for babies born at the threshold of viability has considerable impact on health-care resources. The Neonatal Research Network has demonstrated that babies born below 26 weeks' gestation spend at least 111 days in hospital during infancy at a cost of more than £100 000 (Yeaney et al, 2009). Beyond hospital care, both financial and emotional burdens on families and community support networks are considerable.

Multiple pregnancy rates have increased as consequence of advances in assisted reproduction techniques. Twins and higher order births have a greater risk of complications during and after pregnancy and an increased risk of stillbirth, perinatal mortality and neonatal mortality compared with singletons (Confidential Enquiry into Maternal and Child Health, 2009). Although the current Human Fertilisation and Embryology Authority (2003) guidelines limit the number of embryos to two for women <40 years of age, they have proposed a goal of limiting multiple birth rates as a result of in vitro fertilization to less than 10% by 2011.

Maternal risk factors for perinatal and neonatal mortality

Certain maternal socio-demographic characteristics as well as earlier gestational age and lower birth weight are significantly associated with neonatal death (Ashton, 2006; Singh and Kogan, 2007). Stillbirth, perinatal and neonatal mortalities also vary considerably with maternal age. Women aged <20 years have a significantly higher rate of neonatal death (4.4 per 1000 maternities) and in 2007 teenage maternities contributed 9.6% of the overall neonatal mortality in England, Wales and Northern Ireland (Confidential Enquiry into Maternal and Child Health, 2009). Nationwide there is an increasing trend towards later motherhood. Women aged >40 years have an increased rate of stillbirths and the second highest rate of neonatal deaths. Variations in outcome linked to maternal age may be the result of more frequent pregnancy complications.

Pre-pregnancy body mass index measurements in underweight, overweight, obese and very obese women have shown that increased body mass index is linked to an increased risk of stillbirth and neonatal death (Confidential Enquiry into Maternal and Child Health, 2009). There is a 3.5-fold increase in admission rate to neonatal intensive care units of babies born to mothers who have a body mass index >30 kg/m^2. The Centre for

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Maternal and Child Enquiries is currently conducting a national obesity in pregnancy project, completion of which is expected in 2011.

Non-white ethnicity has been associated with increased risk of stillbirth and neonatal death. Although women of white ethnic origin constitute the largest numbers of maternities in England, neonatal mortality rates in black and Asian women are twice as high as those for women with white ethnicity. It would be over-simplistic to attribute this excess in mortality to ethnicity alone as differences in social deprivation, diet and incidence of diabetes may also occur.

Maternal social deprivation is associated with an adverse neonatal outcome (Bambang et al, 2000; Jorgensen et al, 2008). Neonatal mortality in women living in the most deprived areas is twice that of women living in the least deprived (Confidential Enquiry into Maternal and Child Health, 2009).

Causes of neonatal deaths

The highest cause-specific neonatal mortality is in babies born before 37 weeks (1.3 per 1000 live births). Next come babies with congenital malformation (0.7 per 1000 live births), babies who died as a result of a catastrophic event during labour and babies who had a diagnosis of infection (both 0.3 per 1000 live births) (*Table 1*).

The development of clinical networks

Approximately 10% of babies born every year will require specialist care (Confidential Enquiry into Maternal and Child Health, 2009) and 70 000 babies and their families rely on neonatal services each year in England alone. Advances in neonatal care have improved the survival rates of immature infants but at considerable cost to health-care resources. In response to the increasing numbers of extremely preterm babies surviving at delivery requiring complex, specialist neonatal care, reports from both the Department of Health and National Service Framework for Children, Young People and Maternity Services recommended that neonatal and maternity care be provided in managed clinical networks (Department of Health, 2003). There was significant financial investment to achieve this. Clinical networks were defined as:

> **'Linked groups of health professionals from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and trust/health authority boundaries, to ensure equitable provision of high quality and clinically effective services' (Baker and Lorimer, 2000).**

Twenty-four neonatal networks were set up across England, each consisting of several hospitals providing appropriate designated levels of care. *Table 2* describes the three tiers of neonatal care as described by the British Association of Perinatal Medicine (2001).

Networks were initially designed to offer families and their babies an appropriate level of specialist care at a centre as close to home as possible. While providing local access to appropriate levels of care, networks should improve the quality of care received ensuring seamless pathways of care across all levels. To ensure this provision each network should have standardized care protocols and guidelines including those for rapid and effective communication between each service and the professionals involved. Each network would have at least one level 3 unit where expertise is concentrated to provide care for complex pregnancies and for premature or sick newborns. It is envisaged that each network will develop a transport service ideally moving mothers at high risk of delivering a baby in need of intensive care, a relatively short distance within the network but before the baby's delivery, as described in the Safer Childbirth report (Royal College of Obstetricians and Gynaecologists et al, 2007). This practise would allow the amalgamation of professionals and other resources with the most skill at one regional centre of expertise.

Table 1. Describing cause-specific mortality rates for England, Wales and Northern Ireland 2007

	Early neonatal deaths		Late neonatal deaths		Total neonatal deaths	
Cause of death	**Number**	**Rate (95% CI)***	**Number**	**Rate (95% CI)***	**Number**	**Rate (95% CI)***
Congenital malformation	385	0.5 (0.5–0.6)	152	0.2 (0.2–0.2)	537	0.7 (0.7–0.8)
Death from intrapartum causes	215	0.3 (0.3–0.3)	17	0.0	232	0.3 (0.3–0.4)
Immaturity	822	1.1 (1.1–1.2)	141	0.2 (0.2–0.2)	963	1.3 (1.3–1.4)
Infection	120	0.2 (0.1–0.2)	92	0.1 (0.1–0.2)	212	0.3 (0.3–0.3)
Other specific causes	123	0.2 (0.1–0.2)	35	0.0 (0.0–0.1)	158	0.2 (0.2–0.3)
Accident or non-intrapartum causes	1	0.0	1	0.0	2	0.0
Sudden infant death	21	0.0	18	0.0	39	0.1 (0.0–0.1)
Unclassifiable	19	0.0	12	0.0	31	0.0 (0.0–0.1)
Not known	69	–	27	–	96	–

*Rate per 1000 live births. From Confidential Enquiry into Maternal and Child Health (2009). CI = confidence interval

Clinical networks and their impact on perinatal and neonatal mortality

There are still considerable differences in neonatal mortality rates across networks. As discussed, the predilection for prematurity and neonatal illness is dependent on an array of complex factors including social deprivation, maternal age and ethnicity.

The Confidential Enquiry into Maternal and Child Health (2009) perinatal mortality report for 2007 identifies expected differences in neonatal mortality between the three categories of neonatal care (*Table 2*). Level 1 units having the lowest average neonatal mortality rates (0.8/1000 live births) and level 3 units having the highest average mortality rate of 2.9/1000 live births. Level 3 units work in partnership with obstetric units providing more specialist levels of care to women with high-risk pregnancies and, therefore, have a more complex case mix of more premature and sicker babies. It is less easy to explain and resolve variations in mortality rates between units providing the same levels of care. This variation in mortality rate may be accounted for by units offering sub-specialist services, for example level 3 neonatal surgical units have a caseload of babies at extremely high risk of neonatal mortality.

There are startling differences in perinatal mortality across primary care trusts. Between 2003 and 2005 inclusive the perinatal mortality rate across primary care trusts ranged from 3.9/1000 live births to 16.6/1000 live births (Yeaney et al, 2009).

The differences in perinatal and neonatal mortality at a regional level and, more specifically, at primary care trust level have been reviewed. Freemantle et al (2009) demonstrated a prognostic model for the prediction of infant and perinatal mortality across primary care trusts and showed that 70–80% of between primary care trust variability in infant and perinatal mortality can be explained by a combination of deprivation, ethnicity and maternal age. Differences in primary care trust spending, either between primary care trusts or over time, do not reliably explain differences in rates of infant and perinatal mortality.

Congenital abnormalities resulting from genetically inherited disorders are seen more frequently in populations where there are multiple first cousin marriages, resulting in the expression of gene malformations secondary to recessive genetic modes of inheritance. Increased social deprivation contributes further to increased fetal loss and neonatal mortality rates. These factors co-exist within some populations across the UK, particularly within urban locations.

It is important that health-care practitioners improve their understanding of changing demographics within their locality, and target intervention and prevention strategies at identified high-risk groups for whom services should be appropriately modelled.

Table 2. The British Association of Perinatal Medicine three tiers of intensity of neonatal care

Level 1	The unit provides special care but does not provide any continuing high-dependency or intensive care (27% of all neonatal units)
Level 2	The unit provides high-dependency care and some short-term intensive care as agreed within the regional network (43% of all units)
Level 3	A highly specialized neonatal intensive care unit, provides the whole range of medical neonatal care, but not necessarily all specialist services such as neonatal surgery (30% of all units)

From British Association of Perinatal Medicine (2001)

Performance review and the future of the neonatal network

In 2008, the impact of the Department of Health neonatal intensive care review of 2003, and the evolution of the neonatal clinical networks were assessed. In anticipation of this assessment the National Audit Office (2007) produced a report: *Caring for vulnerable babies; the reorganisation of neonatal services in England*. This report highlighted improvements and changes in neonatal care since the development of neonatal networks, and also indicated some shortcomings. There were serious capacity and staffing problems. Variable states of financial management with mismatches in costs and charges both within and between networks were realized. Although in many areas parents appeared satisfied with the care their babies received, a lack of reliable data made it difficult to gain objective measures of the quality of service. Evidence of outcomes other than mortality rates was incomplete and sparse.

It was apparent that some headway had been made, neonatal mortality trends continued to fall, communication and coordination between units had improved, the development of transport services was underway and there had been a reduction in long distance transfers. The development of effective clinical networks has been challenging (Marlow et al, 2007). The networks evolved at different rates and were slow to re-designate units to meet the demand for individual levels of care. There are unexplained variations in mortality rates and outcome data between networks, and data sets were mismatched and incomplete.

In February 2008, senior members of the Department of Health and NHS were called to the Public Accounts Committee to discuss how the investment in newborn care from the Department of Health had been used and how effective changes to neonatal services had been. In June 2008, a report from the Public Accounts Committee was published, raising questions about service provision and how funding had been spent.

The report recommendations highlighted the importance of communication and cooperation between specialist services commissioning groups and the networks. Primary care trusts were encouraged to recognize the changing demographics of their individual populations and to re-model neonatal services accordingly. Emphasis was placed on the importance of prevention strategies in high-risk groups.

In return neonatal networks have been tasked with demonstrating correctly-staffed units providing the designated level of care. The strategic health authorities are to set measures of and review performances. Neonatal nurse shortages should be addressed with recruitment and retention initiatives.

Transport services within and between networks should be strengthened; the National Cot Locator, a system for identifying available cots outside individual networks, must be improved and used by all networks.

The neonatal taskforce

In the wake of the reports from the National Audit Office and the Public Accounts Committee, the neonatal taskforce was set up early in 2008 jointly between the NHS and Department of Health. Its chair was Professor Sir Bruce Keogh, NHS Medical Director, and its membership included representatives from networking user groups and Department of Health colleagues. The primary aim of the neonatal taskforce was to drive and support strategic health authorities in delivering the improvements needed in their networks. It was a time-limited venture which was completed at the end of 2009. The taskforce divided its work into four working groups: workforce, transfers, surgery and data for commissioning. The groups are chaired by NHS members of the taskforce. BLISS, the premature baby charity, is represented in each of the four groups. Each group was asked to ensure that family-centred care and communications were integral to its work. Within these four groups the taskforce will develop standards of care and a standardized audit of outcome.

The taskforce has produced two key documents: a set of standards for neonatal care encompassing the key areas defined by the four working groups and defining expectations of services provided by the networks and a commissioning framework outlining how these standards should be met. The taskforce has preliminarily set eight standards of care encompassing the provision of and staffing for neonatal services. The transport of mothers and babies both within and between networks has been defined, patient and family experience has been considered. In addition, clinical governance has been addressed alongside training and development issues. A robust clinical governance framework will enable standards of care to be maintained, support innovation and excellent practice, and ensure high accountability for safe practice.

Lord Darzi's (2008) review *High Quality Care for All* and the National Institute for Health and Clinical Excellence have further driven the setting and implementation of quality standards. The Darzi review highlighted the lack of clarity surrounding high quality care as a significant barrier to delivering quality services. In July 2009, neonatal care was one of four areas identified for the setting of quality standards. National Institute for Health and Clinical Excellence quality standards are designed to be the benchmark standards for quality care. This does not extend to practice by individual professionals, although the two should be closely aligned.

The first standards should be available from this pilot project early in 2010 clarifying what high quality care should look like in three key areas of the neonatal service: clinical effectiveness, patient safety and patient experience.

Barriers to progression

In the public eye and to a proportion of health-care professionals the simple strategy of centralization of care may only seem to fragment the local health service. Evidence from other countries that centralization of care is successful in improving neonatal morbidity and mortality has been disregarded based on an argument that these studies are not specific to the UK population (Marlow et al, 2007). Anecdotally, units at district general hospitals have felt disrespect and a lack of recognition for their current standards of care and consequently have often been resistant to the designation of levels of care. Level 2 units, often with 3–4000 deliveries/year, will still need the facilities and expertise to provide short-term intensive care of a high standard. Delivery suites aligned with level 3 units in turn will need to accept a requirement for increasing patient capacities and the increased frequency of the 'in utero' transfer. The neonatal network should be superseded by a true 'perinatal network' as outlined by Marlow et al (2007).

Each region will need many more special care cots than high dependency unit or intensive care unit cots, as relatively few neonatal admissions will require full intensive care unit facilities. Taking this into consideration, re-assigning significant workload from multiple district hospitals to a single tertiary centre may swamp a tertiary centre that does not have effective and appropriate funding. The issues of funding are in themselves complex, should a clinical network be a provider of clinical care or a commissioner for its own services? Parents and the public must be involved in both an advisory and decision-making capacity in these complex but relevant changes, however, they need to be guided in an unbiased manner.

Addressing the national shortage of both neonatal nurses and midwifery staff is of uppermost importance. Networks must accommodate both training and recruitment programmes, these areas of concern at both medical and nursing staffing levels will become increasingly apparent with the implementation of the European Working Time Directive.

How the taskforce standards will impact on perinatal and neonatal mortality

The ideology behind clinical networks is not new. Successful network practises have been established in other medical specialties such as oncology. It is apparent

that the development of coordinated clinical networks is paramount in improving the quality of care and level of expertise available to the neonatal, and in particular the preterm, population. The true measure of effectiveness of the neonatal networks would be further reduction in perinatal or neonatal mortality, however, in the short term this is perhaps an unobtainable goal. Nationwide collection of data has been poor.

As a consequence, in 2006 the National Neonatal Audit Project was set up. Its primary aims were: to assess whether babies requiring specialist neonatal care receive consistent high quality care across England and Wales, to identify areas for improvement in relation to service delivery and the outcomes of care and to set up a mechanism for ensuring consistent high-quality care in neonatal services in the future. The collection, both locally and nationally, of complete and concise data and relevant analysis and response to datasets will be paramount in the drive towards a unified quality of care available nationally, this in turn impacting perinatal and neonatal mortality.

Conclusions

The current influence on perinatal and neonatal mortality is not just that of developing medicine and neonatal care. It is the establishment of managed networks promoting primary health prevention, identifying and responding to local demographics, making available complex specialist care of the highest calibre. Only when this practise is established, effectively harnessing resources and manpower, will the innovative advances in key areas of neonatal care begin to further reduce perinatal and infant mortality. BJHM

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Conflict of interest: none.

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KEY POINTS

- The neonatal period has one of the highest mortality rates of any period of life, and is currently 3.3/1000 live births in the UK.
- The most common cause of neonatal mortality in the UK is prematurity.
- In 2003, following reports from the Department of Health and National Service Framework, it was recommended that neonatal care be provided in managed clinical networks.
- The development of newborn networks should facilitate improvements in neonatal care and drive improvements in perinatal and neonatal mortality rates.
- In 2008, in the wake of reports from the National Audit Office and the Public Accounts Committee highlighting deficiencies in newborn services, the neonatal taskforce was established to deliver service improvements within newborn networks.
- Neonatal care has been identified as one of four key areas for setting quality standards. The National Institute for Health and Clinical Excellence will use the principles of care developed by the neonatal taskforce and present them as standards.