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TECHNICAL REPORT

The provision of neonatal services

Data for international comparisons

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Prepared for the National Audit Office

The research described in this report was prepared for the National Audit Office.

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Summary

1. The National Audit Office (NAO) is undertaking a Value for Money study of neonatal services in England. As part of this study, RAND Europe was commissioned to generate relevant data to supplement the evidence that the NAO gathers on England.
2. This report describes the provision of neonatal services in the UK nations of Scotland, Wales, Northern Ireland, and the United States of America, Canada, Sweden, and Australia. Its main purpose is to provide a compendium of relevant data to facilitate comparisons and benchmarking of neonatal services (organisation, statistics, and so on) in England with the above nations. The report does not consider the provision of neonatal services in England itself, although it does compare relevant statistics for England against the countries named above. Since the report is concerned with international comparisons, it does not analyse differences within countries.
3. The RAND Europe study collected data in a structured and systematic way that reflected five research dimensions, which were identified by the NAO. These dimensions were: 1) statistics on trends in high-risk births and associated outcomes, including mortality and co-morbidities; 2) the organisation and scale of neonatal services; 3) neonatal transport services; 4) costs of neonatal services and 5) best practices for infants and their families.
4. This summary chapter provides the main findings of the study. Chapter Two provides wider inter- and intra-country analysis and comparisons. Chapters Three to Nine provide more specific and detailed information on the various countries studied.

Neonatal intensive care improves the prognoses of its patients

5. Neonatal intensive care increases the survival rates of newborns, particularly those with low birth weight or gestational age. Effective neonatal care also improves morbidity rates, improving the long-term health prospects and quality of life for premature or low birth weight babies. In doing so the long-term burden on state sponsored health and social care systems is reduced.
6. The improvement in the prognosis of very preterm infants during the last decades has been attributed primarily to improvements of neonatal intensive care, including the introduction of surfactant and antenatal steroid therapy. For example, a U.S. study found that two-thirds of the decline in mortality among Very Low Birth Weight (VLBW) infants observed during the early 1990s could be attributed to increases in the effectiveness of

newborn intensive care.⁵ However, there has been a much slower improvement in mortality or morbidity rates in recent years.

Comparing neonatal care across countries is problematic, yet can generate useful information

7. It is difficult to compare neonatal care across countries and regions. Substantial disparities in populations, geographies and access to services must be taken into account. In addition, comparisons of neonatal morbidity and mortality require effective measures for adjusting for varying population health characteristics. Each country structures its health services differently, according to variations in history and underlying political philosophies. Contrasting amounts and types of information are available for each country because of their distinct information infrastructures and reporting mechanisms. There is no co-ordinated data set that countries are required to gather, nor are the parameters of particular data always the same. For example, babies may be considered premature if born before 32 or 37 weeks' gestation.
8. Nevertheless, the comparisons that are possible can provide illuminating results. Comparisons can offer a wider context for assessing performance and highlight possible benchmarks for evaluation practices. They can suggest innovative practices for improving performance, both at the level of patient care and at the level of service organisation.

Perinatal, neonatal and infant mortality rates in England appear to be within a similar range to the other countries compared

9. Our analysis of statistics and trends related to neonatal care suggests that England has rates of perinatal, neonatal and infant mortality that are similar to those found in Scotland, Wales, Northern Ireland, Australia and Canada. Mortality rates are consistently higher than this group in the U.S., and consistently lower in Sweden.
10. Broadly speaking, there has been an overall downward trend in mortality rates for the countries studied, including England.
11. Demand for neonatal services in England (measured by the proxy of low birth weight births) is similar to Scotland, Wales and the U.S., and significantly higher than Australia, Canada and Northern Ireland. The rate of low birth weight births is much lower in Sweden than in all other countries studied.

All the countries use some neonatal networks in the provision of neonatal services, although these networks are formalised to varying degrees

12. In England, Northern Ireland, Scotland and Wales, neonatal services are provided by the branch of the National Health Service (NHS) dedicated to that region, and therefore are funded and overseen by the regional government. In the UK, only England has a formal neonatal clinical network, although some units, particularly in Scotland and Northern

⁵ Richardson, D., *et al.* (1998), 'Declining Severity Adjusted Mortality: Evidence of Improving Neonatal Intensive Care', *Pediatrics* 102:4, 893-99.

Ireland, do utilise an informal networked approach due in part to the geographical distribution of the units.

13. As might be expected from their large geographical area, the U.S., Australia and Canada have highly regionalised neonatal services, provided at the state or sub-state level. The organisation of neonatal networks is based on the demand for care and the ability to supply such care, both of which are affected by geographical factors. In these three countries, regional networks have developed their own practices of neonatal service provision that reflect the region's population size and distribution, its geography, history and culture, and its current political, legal and financial situation.
14. Of the countries considered in this report, only Sweden is moving towards a more centralised system of neonatal care. Although the Swedish health care system is mainly region-based, neonatal intensive care is increasingly centralised due to the relatively few children that require neonatal intensive care.

Low staffing is a pervasive problem for UK neonatal services

15. Low staffing levels is a pervasive problem in UK neonatal services: all three regions of the UK fall short of the recommended staffing levels laid down by the British Association of Perinatal Medicine (BAPM). Scotland is well-staffed at consultant level, but lacking in neonatal nurses. Northern Ireland has a particular deficit of nurses, and staffing levels in Wales are critical at both the consultant and specialised nursing levels. In particular, there is evidence that the absence of dedicated neonatal transport teams produces staffing problems on neonatal wards. Across the UK as a whole in 2006, 78 per cent of neonatal units had to turn babies away because of lack of capacity. This figure is eight per cent higher than in 2005.
16. There was little evidence of shortages in staffing or cots in the non-UK neonatal networks considered in this report. However, in Canada, the demand for neonatal intensive care unit (NICU) beds sometimes exceeds the number officially available, and this may be aggravated by nursing shortages; there is also some concern that the number of nurses nationwide in the U.S. is low.

Neonatal transport teams may be co-ordinated centrally for a regional network or may be affiliated to a tertiary care institution

17. Broadly speaking, neonatal transport teams are provided either in a centrally co-ordinated, formal structure, servicing all the hospitals in a specified region, or they are maintained by regional tertiary care institutions and retrieve neonates for transport to that institution. This is rather a crude distinction, since there are many varying degrees of network organisation between these two variants.
18. It appears that the centrally co-ordinated transport teams generally exist in regions that have developed networks that are more sophisticated in other respects, and they are often supported by effective information-gathering and communications structures. This is true for the networks in California, British Columbia, Victoria and New South Wales, for example. Of the three UK regions, only Scotland has designated neonatal transport teams, and a centralised transport network.

19. There are three basic models of transport team dealing with neonatal transfers: specialist neonatal teams; paediatric teams; and unified paediatric/neonatal teams. The existence of one or more of these team types varies greatly according to networks. Sweden has no specialised neonatal transport teams, but its ambulance services are locally based and organised in close contact with local health centres, ensuring they are responsive to changing needs.

Only a few countries report systematically on the cost of neonatal service provision

20. Obtaining aggregated cost data for countries is problematic, since reporting structures vary greatly between countries. The countries that provided the best nationwide data were generally those with some form of universal health care system, but this was not always true. The financial structure of the U.S. health system means that administrative records are geared towards measuring charges rather than costs.
21. Most of the cost data available was provided at a regional level, or referred to a particular institution that had been the subject of an academic study. The studies were conducted across varying time periods and used different currencies, and therefore it is not possible to make meaningful quantitative comparisons. However, the major debates regarding neonatal costs concern expenditure on babies at the limit of survival viability, and how much of neonatal spending should be directed towards technologies, rather than other elements of care.

Evidence suggests that British Columbia, Victoria, New South Wales and California lead the way in the development of high-quality neonatal service provision

22. As noted above, regional neonatal networks vary within and between countries because of geographic, demographic, financial and historical factors. The evidence gathered for this study suggested that there were four regions that had evolved particularly sophisticated neonatal networks: British Columbia, Victoria, New South Wales and California. The elements that constitute this quality and sophistication include: communications and administration systems; transport techniques; centralised decision-making and oversight bodies; data sharing infrastructures; best practice guidelines; reporting mechanisms (both inside and outside the network); the use of consultative committees; procedures to boost family involvement; quality improvement provisions; and evaluation exercises (in particular, those allowing benchmarking).
23. The highlighting of these three regional networks does not mean that other networks are poor. Some networks that serve smaller, or more dispersed, populations, and which contain a limited number of institutions, may rely on more informal networking practices because economies of scale do not justify the costs of formalising these practices.
24. Furthermore, it is more difficult to highlight the practices of particular networks when they are subsumed within a global structure such as the UK's National Health Service. However, the evidence suggested that the infrastructure supporting neonatal services in Wales is less developed than in Scotland or Northern Ireland, with an absence of

systematic data collection, and no dedicated neonatal transport system. However, the causal impact of this less developed infrastructure on neonatal mortality rates is not clear, and may require further analysis.

25. Best practice guidelines were issued by a combination of medical associations, government agencies, or individual hospitals. The source and existence of government guidelines varied across countries: when they existed, they were either issued by national or regional bodies, and contained varying levels of detail. All the non-UK countries studied adhered to a basic Level I/II/III care structure, but equally these countries reported that the interpretation and implementation of this structure varied greatly between regional networks.