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NORTH EAST PUBLIC HEALTH OBSERVATORY

RMSO
REGIONAL MATERNITY SURVEY OFFICE

# Northern Regional Maternity Survey Office Annual Report 2003

## including final data for 2002 and provisional data for 2003

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# SUMMARY MORTALITY RATES

Northern Region 2001, 2002 (final), 2003 (provisional): Summary of perinatal and infant mortality data (RMSO) and number of births (ONS). 2002 & 2003 Data for England & Wales (ONS)

| | NORTHERN REGION | | | ENGLAND & WALES | |
|---|---|---|---|---|---|
| | 2001 | 2002 | 2003 | 2002 | 2003 |
| BIRTHS | | | | | |
| Total | 29159 | 29391 | 30329 | 599494 | 625054 |
| Live | 29006 | 29208 | 30158 | 596122 | 621469 |
| STILLBIRTHS | | | | | |
| Number | 153 | 183 | 171 | 3372 | 3585 |
| Rate (/1000 total births) | 5.2 | 6.2 | 5.6 | 5.6 | 5.8 |
| PERINATAL DEATHS | | | | | |
| Number | 227 | 248 | 243 | 5005 | 5319 |
| Rate (/1000 total births) | 7.8 | 8.4 | 8.0 | 8.3 | 8.5 |
| EARLY NEONATAL DEATHS | | | | | |
| Number | 74 | 65 | 72 | 1633 | 1734 |
| Rate (/1000 live births) | 2.5 | 2.2 | 2.4 | 3.6 | 2.8 |
| LATE NEONATAL DEATHS | | | | | |
| Number | 29 | 23 | 29 | 504 | 514 |
| Rate (/1000 live births) | 0.9 | 0.7 | 0.9 | 0.8 | 0.8 |
| POST-NEONATAL DEATHS | | | | | |
| Number | 51 | 45 | 53 | 1031 | 1058 |
| Rate (/1000 live births) | 1.7 | 1.5 | 1.7 | 1.7 | 1.7 |
| INFANT DEATHS | | | | | |
| Number | 154 | 133 | 154 | 3168 | 3306 |
| Rate (/1000 live births) | 5.3 | 4.6 | 5.1 | 5.3 | 5.3 |

Note: The Northern Region is the geographical area covered by Northumberland, Tyne and Wear Strategic Health Authority and County Durham and Tees Valley Strategic Health Authority plus "North Cumbria" (Carlisle and District PCT, West Cumbria PCT and Eden Valley PCT).

# CONTENTS

# 1. INTRODUCTION

## This report

This is the twenty-second annual report produced by the RMSO. The reports have changed in format over the years but the aims of the report remain the same:

- To provide clinical staff involved in the care of women and children with timely epidemiological information about adverse outcomes of pregnancy;
- To inform relevant NHS professionals and managers about the data held by the RMSO and how this can be used to support audit and clinical governance in the NHS;
- To provide information on how data held by the RMSO is being used for epidemiological and health care research.

Each chapter provides an update on one of the surveys and how data are being used. There are also chapters on service delivery covering autopsy, maternity care and neonatal intensive care. Considerable detail is provided in Chapter 6 on an in depth analysis of the data held by the Diabetic Pregnancy Survey.

## Key messages from the report

- The 1990s saw a fall in both the numbers of births and the crude livebirth rate in this region as elsewhere and this continued until 2001. However, the total births for 2003 were again slightly higher (30 329) than in 2002 (29 394) and 2001 (29 159).
- Unexplained antepartum stillbirth remains the major contributor to perinatal death (chapter 2).
- Unsuspected/undiagnosed conditions were demonstrated in over 50% of autopsies following stillbirth, with the majority of these having implications for future pregnancies. However overall perinatal autopsy rates remain at only 46% of deaths with variation between units from 15% to 80% (chapter 3).
- There is a need for a shared approach across the region to the management of Sudden Unexpected Death in Infancy (chapter 4).
- Nationally the leading overall cause of maternal death is suicide. The leading cause of direct deaths is thrombosis and thromboembolism. The maternal mortality rate in the UK is 13.1 per 100,000 maternities. Of all deaths in women of childbearing age in the UK, only 1.5% of deaths are classed as maternal (chapter 5).
- Poor glycaemic control before and during pregnancy leads to increased risks for perinatal mortality and congenital malformation and for poor obstetric outcomes (chapter 6).
- In 2003, three maternity units exceeded three thousand deliveries per year and a further two exceeded two thousand deliveries. The three smallest units showed significant falls in their delivery rate. Obstetric intervention rates were essentially unchanged from 2002 other than a small increase in caesarean section rates (from 16.9% to 18.6%) (chapter 7).

- Obesity presents real risks to pregnant women and their babies, with obese women having a higher risk of pregnancy complications and their babies being more likely to have congenital anomalies or to be stillborn (chapter 8).
- Neonatal intensive care workload continues to rise. There has been a significant increase in survival (to discharge) since 1996 of babies born at 25 to 26 weeks gestation (chapter 9).
- The twinning rate in 2002 was 16.6/1000 maternities compared with 9.8/1000 in 1990 and 14.5/1000 in 2000.
- Problems remain with ascertainment by the National Congenital Anomaly System (NCAS). This will be markedly improved by notification via the regional registers including NorCAS. However only half of England is covered by regional registers (chapter11).
- The North of England Collaborative Cerebral Palsy Survey (NECCPS) is measuring participation and the impact of disability and is developing positive models for working with parents (chapter 12).

## The Regional Maternity Survey Office (RMSO)

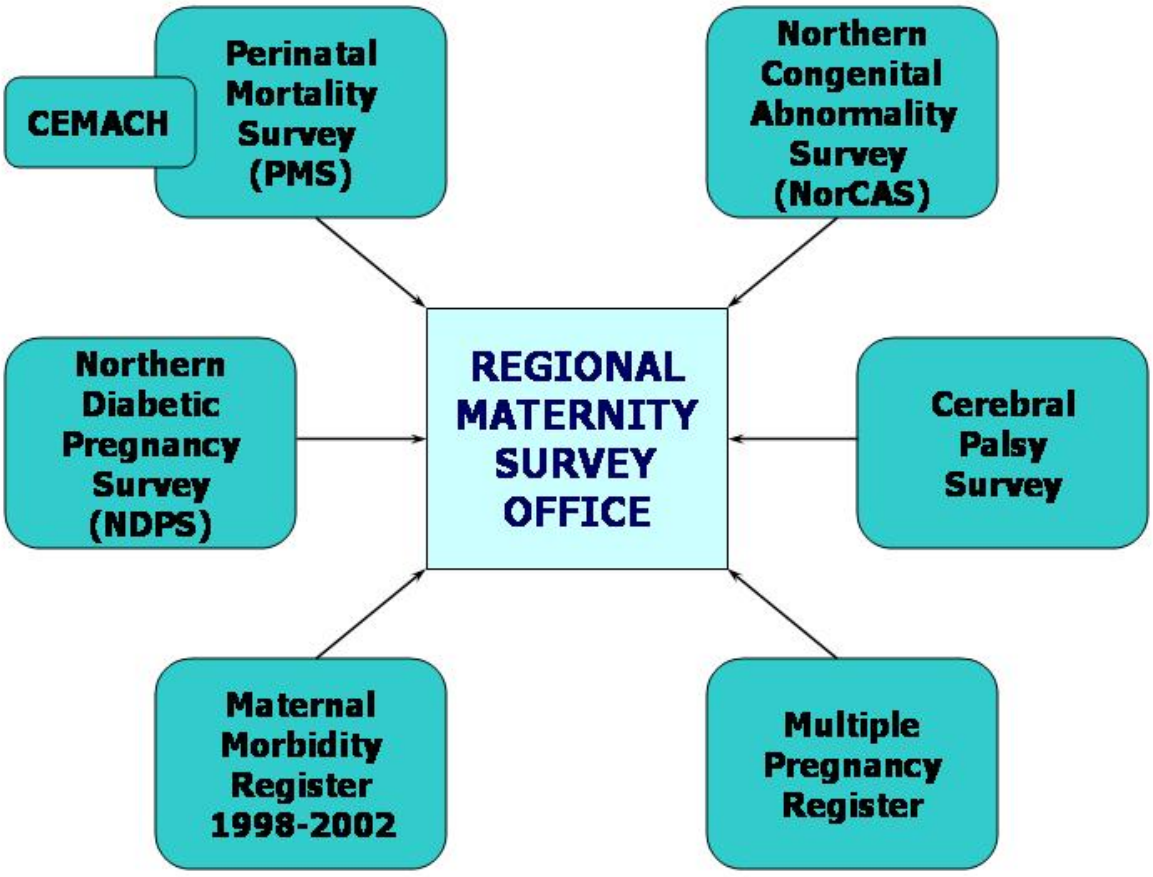
The Northern Regional Perinatal Mortality Survey was established in 1981 with the aim of studying perinatal mortality and its causes. In 1985, the Fetal Abnormality Survey (now the Northern Congenital Abnormality Survey - NorCAS) was established with the remit of obtaining data on congenital abnormality in the Northern Region. From 1993, the Regional Maternity Survey Office (RMSO) delivered the regional co-ordination function for the national Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), including both data collection and running confidential enquiry panels. From April 2003, the RMSO has delivered these functions for the new Confidential Enquiry into Maternal and Child Health (CEMACH) which replaces CESDI and the Confidential Enquiry into Maternal Deaths.

In recognition of the importance of studying morbidity, the RMSO has also hosted a Multiple Pregnancy Register since 1998. The Regional Diabetic Pregnancy Survey (established in 1994) was incorporated into the RMSO during 1999. In addition, the RMSO has hosted the North of England Collaborative Cerebral Palsy Survey (NECCPS) since 1995 (Figure 1.1).

From January 2003, the RMSO has been the reporting route for the National Congenital Anomaly System (NCAS) and from late 2004 has provided anonymised data for the European Surveillance of Congenital Anomalies (EUROCAT).

Since April 2002 the RMSO has been part of the North East Public Health Observatory (NEPHO).

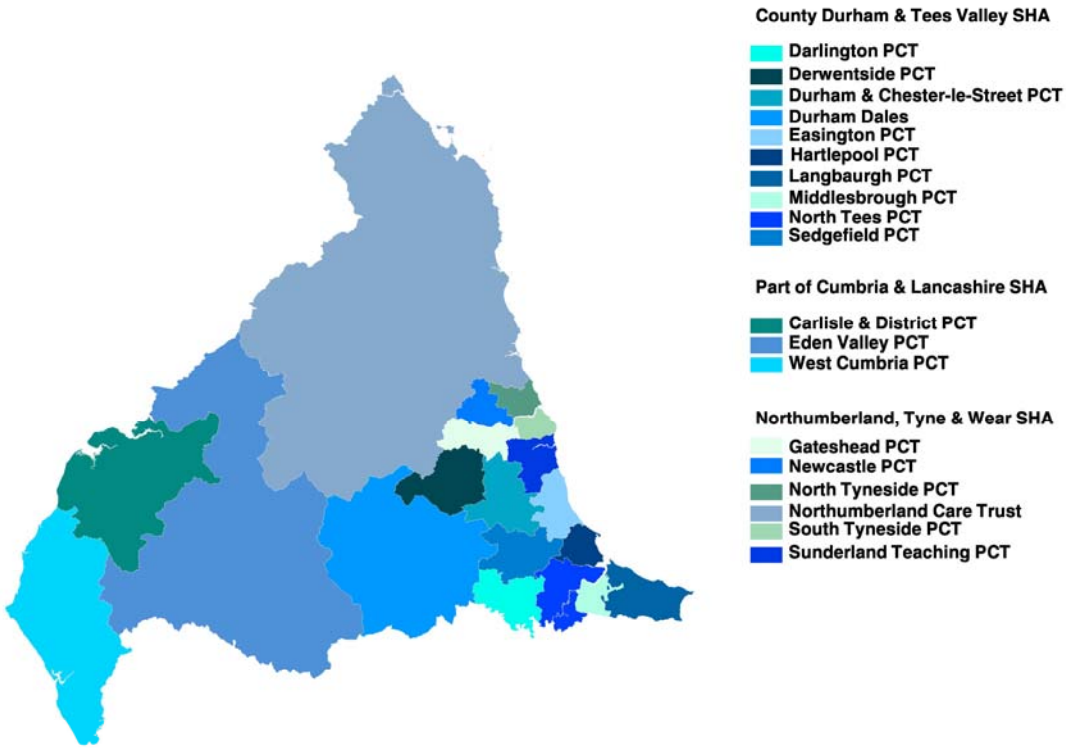
Figure 1.1: The Surveys and Registers



### *Boundaries for data collection and reporting*

This is the second report produced by the Regional Maternity Survey Office (RMSO) since it became part of the North East Public Health Observatory (NEPHO). Major changes occurred to NHS organisations in 2002, with the formation of Primary Care Trusts (PCTs) and Strategic Health Authorities (Map 1.1) and the abolition of Health Authorities and the NHS Regional Offices. PCT populations are defined as those registered with a General Practitioner in the PCT plus any unregistered population.

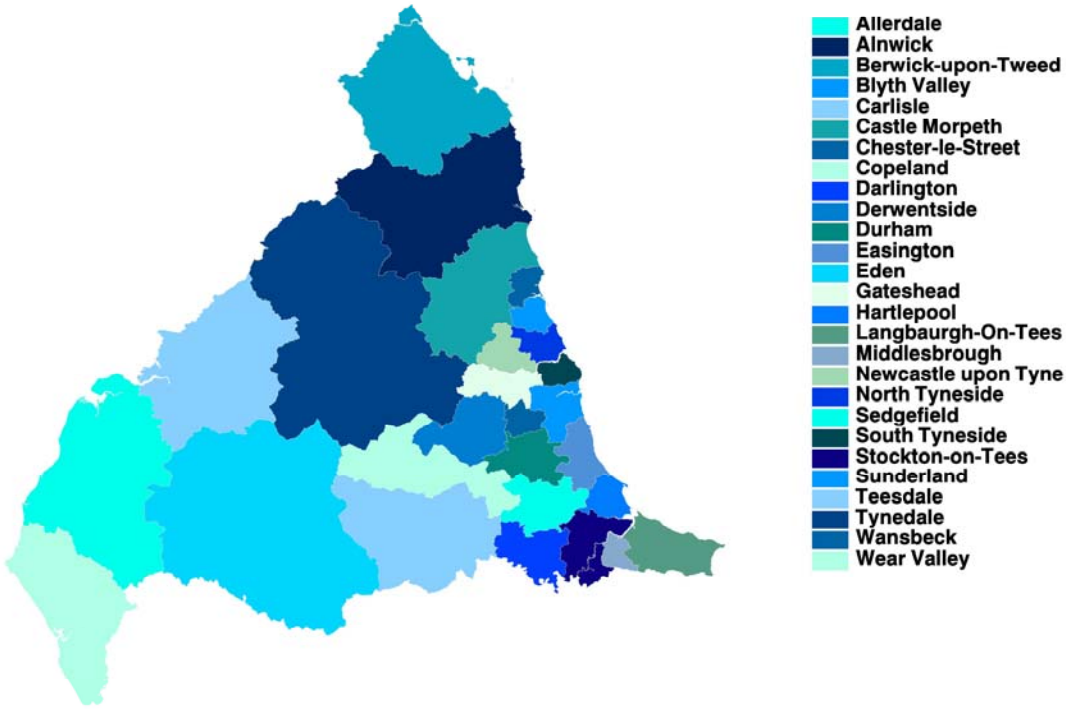
Map 1.1: Strategic Health Authorities and PCTs covered by the RMSO




**This map is based on data provided with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown.**

The RMSO has always reported data to geographical boundaries as this is essential for comparison with national data sources. In this report, data are presented mostly by Local Authority (map 1.2). Local Authority has been chosen as this provides a reasonable match with PCT geographical populations and a number of relevant national targets are now defined at Local Authority level.

Map 1.2: Unitary and district authorities covered by the RMSO




**This map is based on data provided with the support of the ESRC and JISC and uses boundary material which is copyright of the Crown.**

### *Consent and confidentiality*

As a member of the British Isles Network of Congenital Anomaly Registers (BINOCAR), the Northern Congenital Abnormality Survey (NorCAS) obtained Section 60 Approval (Health and Social Care Act, 2001) to process data. Section 60 approval has also been obtained by CEMACH for the national and regional components of its work. Patient consent is obtained for data collection for the Diabetic Pregnancy Survey and the NECCPS. Mechanisms for consent for the Multiple Pregnancy audit are being explored.

The RMSO Advisory Group was established in 2003 to address issues of consent and confidentiality in relation to the surveys. The RMSO Advisory Group reports on its work in Chapter 13 (see Appendix (ii) for membership).

Data are processed at the RMSO within the parameters of its *Security and Confidentiality Policy.* The RMSO is British Standard 7799 compliant. Access to data is tightly controlled.

Access to data – clinical governance

Senior clinical staff have access on request (and subject to usual data security requirements) to named patient data from their own units for audit and quality control purposes. Directors of Public Health have access to data on their Primary Care Trust/Strategic Health Authority populations on specific request to the Director of the RMSO to address issues of concern.

Access to data – research

Applications to access data for research purposes are made using the RMSO documentation and must comply with RMSO guidance. Requests for access to named data will require Local or Multi Research Ethics Committee approval for the project. Advice is available from the Director or the Clinical Director of the RMSO. The RMSO has always enthusiastically supported research using data from the surveys and registers. A list of recent publications is included in relevant chapters.

## *RMSO funding*

The RMSO currently has three main sources of funding:

- Funding on a capitation basis from the 16 North East PCTs from April 2004;
- Department of Health disease registers grant to support NorCAS;
- CEMACH funding for its regional function for the North East.

Additional funding continues to be sought.

## *RMSO outputs*

The surveys and registers are utilised for:

- Local and regional audit in support of clinical governance in obstetrics, paediatrics and midwifery services across the region;
- As a platform for research into causes of deaths, anomalies and disability and into service quality;
- As the regional component of national (and from 2004, international) surveillance programmes.

In addition two new NHS objectives and performance targets require this data:

- Infant Mortality Inequalities target;
- Monitoring and evaluation of antenatal screening programmes.

The RMSO also provides the regional management function for CEMACH.

The RMSO provides regular feedback through this report and the annual meetings. There are annual meetings for four of the registers/surveys: PMS, NorCAS, NECCPS and the Diabetic Pregnancy Survey. These meetings are used to present work which has utilized the data and to debate controversial and topical issues. Issues from the meetings are highlighted in some of the chapters.

# 2. PERINATAL MORTALITY SURVEY (PMS)

Summary regional data for 2003 and final data for 2002 are presented on page (i).

## Births

The 1990s saw a fall in both the numbers of births and the crude livebirth rate in this region as elsewhere and this continued until 2001. However, the total births for 2003 were again slightly higher (30 329) than in 2002 (29 394) and 2001 (29 159).

## Perinatal deaths and mortality rates

Table 2.1 gives the numbers of registered births (ONS data), perinatal deaths (RMSO data) and perinatal mortality rates in each Local Authority (district and unitary) for the last three years. Some districts show considerable year-to-year variation in perinatal mortality, which to a large extent reflects the relatively small numbers of deaths involved. In an attempt to overcome this, average perinatal mortality rates for the three year periods 2000-2002 and 2001-2003 are provided.

At least some of the variation in perinatal mortality between districts and over time may lie in the numbers of infants with gestations less than 24 weeks judged to have died in the neonatal period (and therefore contributing to perinatal mortality) rather than in utero (classified as a spontaneous abortion). For this reason the WHO and others have recommended that infants less than 500g should be excluded from perinatal mortality statistics. Table 2.2 shows the numbers of perinatal deaths of infants weighing at least 500g; those weighing at least 1kg; those weighing at least 1kg who were also normally-formed; and appropriate perinatal mortality rates for 2002 and 2003 and for 2001-2003. Excluding very low birthweight babies largely removes the contribution of extreme prematurity to perinatal mortality and allows an assessment of the residual mortality for larger infants.

### *Unit data*

Table 2.3 gives timing of death and perinatal mortality rate by hospital maternity unit of delivery. In general terms, district to district comparisons reflect socioeconomic and other population factors and, to a lesser extent, the health care factors (access and quality) resulting in the measured outcome which here is mortality. While unit to unit comparison may allow a closer focus on health care factors, it continues to reflect the underlying population factors. As already noted, it is inadvisable to come to firm conclusions using annual perinatal mortality rates based on relatively small numbers of births. Also, larger units acting as tertiary referral centres would be expected to have more deaths. **For these reasons table 2.3 requires cautious interpretation.** As in previous years, an 'adjusted' perinatal mortality rate has been calculated, which excludes pregnancies either unbooked or originally booked elsewhere.

## Infant mortality

The total numbers of late abortions (20-23 weeks gestation), stillbirths, neonatal and post-neonatal deaths for each local authority during 2002 and 2003 are presented in table 2.4, together with the calculated infant mortality rate (deaths in the first year of life/1000 live

births). Numbers of deaths are small and year on year variation at individual local authority area level is likely to be due to chance.

## Immediate cause of perinatal and infant death

Table 2.5 gives cause of death using the Extended Wigglesworth classification[†] and perinatal and infant mortality rates.

The major contributor to perinatal mortality remains "antepartum death", in the main unexplained antepartum stillbirth which has been extensively investigated through the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI). Both congenital malformation and immaturity also contribute as significant causes.

The most important cause of infant mortality is malformation followed by immaturity and infection. The contribution of SIDS (Sudden Infant Death Syndrome) has reduced from a rate of 1.8/1000 livebirths in 1989-1991 to 0.7/1000 livebirths in 2000-2002 and 0.5/1000 livebirths in 2001-2003.

## Summary of research undertaken with PMS data in the last two years

### *Perinatal mortality in the Northern Region, 1982-2000: the contribution of changing maternal risk factors. (funded by the Newcastle Healthcare Charity; research completed July 2003)*

Whilst perinatal mortality in England and Wales has declined over the past 20 years, the rate remains at a higher level than in many other European countries. Perinatal mortality is known to be higher among teenage mothers, older mothers (>35 years), in multiple births and at low and high birthweights. This research quantified the contribution of secular trends in these factors to the extended perinatal mortality rate in the Northern Region, and found that changes in the risk factor profile have resulted in a higher crude perinatal mortality rate.

Publications arising from this research:

BELL R, GLINIANAIA SV, RANKIN J, WRIGHT C, PEARCE MS, PARKER L. *Changing patterns of perinatal death, 1982-2000: a retrospective cohort study.* Archives of Disease in Childhood Fetal and Neonatal edition 2004; 89: F531-F536.

RANKIN J, PEARCE MS, BELL R, GLINIANAIA SV, PARKER L. *Perinatal mortality rates: adjusting for risk factor profile is essential.* Paediatric & Perinatal Epidemiology 2005 (in press)

GLINIANAIA SV, RANKIN J, BELL R, PEARCE MS, PARKER L. *Contribution of changing risk factors to trends in perinatal mortality: population based retrospective cohort study*. Journal of Clinical Epidemiology 2005 (accepted).

[†] A hierarchical classification system for perinatal deaths, based on nine categories, which is intended to identify a single underlying disease process or mechanism which led to death.

### *The epidemiology of stillbirth 1982-2000 (part funded by Newcastle Healthcare Charity: expected completion date March 2005)*

Around 5/1000 births are stillbirths. The decline in stillbirth rates in England and Wales has slowed in recent years, and in particular concerns have been raised in relation to the lack of improvement in antepartum stillbirths. A large proportion of these cannot be attributed to any specific cause of death. This research aims to describe and explore trends in stillbirth over the past two decades, and to investigate the contribution of maternal and other risk factors.

Publications arising from this research:

BELL R, PARKER L, MACPHAIL S, WRIGHT C. *Changes in the cause of late fetal death,* 1982-2000. BJOG 2004; 111: 1400-1407.

Table 2.1: Northern Region: Perinatal Deaths and Perinatal Mortality Rates 2001, 2002 & 2003 and 3 year rolling average Perinatal Mortality Rates 2000-2002 and 2001–2003, by Local Authority

| Local Authority | Registered Total Births (ONS) | | | Number of Perinatal Deaths (PMS) | | | PERINATAL MORTALITY RATE (per 1,000 Total Births) | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2001 | 2002 | 2003 | 2001 | 2002 | 2003 | 2001 | 2002 | 2003 | 2000/02 | 2001/03 |
| Hartlepool | 1034 | 1016 | 1067 | 4 | 10 | 7 | 3.8 | 9.8 | 6.6 | 8.3 | 6.7 |
| Stockton on Tees | 1956 | 2021 | 2127 | 20 | 12 | 20 | 10.2 | 5.9 | 9.4 | 7.6 | 8.5 |
| Middlesbrough | 1676 | 1707 | 1795 | 20 | 17 | 14 | 11.9 | 9.9 | 7.8 | 9.5 | 9.9 |
| Redcar & Cleveland | 1439 | 1365 | 1454 | 11 | 9 | 11 | 7.6 | 6.6 | 7.6 | 7.9 | 7.3 |
| Darlington | 1083 | 1143 | 1184 | 9 | 8 | 6 | 8.3 | 7.0 | 5.1 | 9.7 | 6.8 |
| Wear Valley | 626 | 654 | 642 | 4 | 12 | 6 | 6.4 | 18.3 | 9.3 | 10.4 | 11.3 |
| Derwentside | 872 | 842 | 886 | 1 | 3 | 12 | 1.1 | 3.6 | 13.5 | 4.6 | 6.1 |
| Durham City | 716 | 804 | 794 | 6 | 7 | 4 | 8.4 | 8.7 | 5.0 | 9.5 | 7.4 |
| Chester le Street | 527 | 552 | 544 | 4 | 1 | 6 | 7.6 | 1.8 | 11.0 | 7.7 | 6.8 |
| Easington | 936 | 994 | 928 | 5 | 8 | 10 | 5.3 | 8.0 | 10.8 | 7.7 | 8.0 |
| Sedgefield | 926 | 899 | 978 | 10 | 9 | 6 | 10.8 | 10.0 | 6.1 | 10.9 | 8.9 |
| Teesdale | 183 | 185 | 191 | 1 | 0 | 3 | 5.5 | 0.0 | 15.7 | 3.4 | 7.1 |
| Sunderland | 2869 | 2947 | 3026 | 23 | 25 | 22 | 8.0 | 8.5 | 7.3 | 8.3 | 7.9 |
| South Tyneside | 1489 | 1474 | 1531 | 19 | 11 | 11 | 12.8 | 7.5 | 7.2 | 9.1 | 9.2 |
| Gateshead | 2010 | 2023 | 2031 | 17 | 14 | 19 | 8.4 | 6.9 | 9.4 | 8.8 | 8.2 |
| North Tyneside | 1955 | 2053 | 2114 | 10 | 17 | 14 | 5.1 | 8.3 | 6.6 | 6.9 | 6.7 |
| Newcastle | 2888 | 2963 | 2913 | 22 | 32 | 25 | 7.6 | 10.8 | 8.6 | 9.0 | 9.0 |
| Northumberland | 2870 | 2781 | 2950 | 23 | 27 | 21 | 8.0 | 9.7 | 6.8 | 8.0 | 8.2 |
| Allerdale | 910 | 847 | 902 | 5 | 6 | 4 | 5.5 | 7.1 | 4.4 | 6.4 | 5.7 |
| Carlisle | 925 | 1044 | 1100 | 5 | 9 | 7 | 5.4 | 8.6 | 6.4 | 6.9 | 6.8 |
| Copeland | 666 | 663 | 696 | 3 | 9 | 9 | 4.5 | 12.7 | 12.9 | 8.4 | 10.0 |
| Eden | 474 | 414 | 476 | 5 | 2 | 6 | 10.5 | 4.8 | 12.6 | 11.0 | 9.3 |
| **NORTHERN REGION** | **29059** | **29391** | **30329** | **227** | **248** | **243** | **7.8** | **8.4** | **8.0** | **8.3** | **8.1** |

Table 2.2: Northern Region 2001 & 2002: Perinatal Mortality by Local Authority excluding infants weighing less than 500g or less than 1kg. Perinatal mortality rates for infants weighing 1 kg or more, both with and without major malformation for 2002 & 2003

| Local Authority | Deaths known to RMSO | | | | | | | | PERINATAL MORALITY RATE | | | PERINATAL MORTALITY RATE | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | All perinatal Deaths | | >499g only | | >999g only | | Normally Formed >999g | | All > 999g | | | Normally-formed > 999g | | |
| | 02 | 03 | 02 | 03 | 02 | 03 | 02 | 03 | 2002 | 2003 | 2001-03 | 2002 | 2003 | 2001-03 |
| Hartlepool | 10 | 7 | 10 | 7 | 9 | 4 | 8 | 2 | 8.9 | 3.7 | 5.2 | 7.9 | 1.9 | 4.2 |
| Stockton on Tees | 12 | 20 | 10 | 16 | 5 | 11 | 3 | 8 | 2.5 | 5.2 | 4.6 | 1.5 | 3.8 | 3.5 |
| Middlesbrough | 17 | 14 | 15 | 13 | 10 | 11 | 4 | 6 | 5.9 | 6.1 | 6.0 | 2.3 | 3.3 | 3.3 |
| Redcar & Cleveland | 9 | 11 | 8 | 9 | 5 | 3 | 5 | 3 | 3.7 | 2.1 | 3.6 | 3.7 | 2.1 | 3.6 |
| Darlington | 8 | 6 | 7 | 5 | 5 | 1 | 5 | 1 | 4.4 | 0.8 | 3.6 | 4.4 | 0.8 | 3.6 |
| Wear Valley | 12 | 6 | 12 | 5 | 10 | 3 | 7 | 2 | 15.3 | 4.7 | 8.3 | 10.7 | 3.1 | 6.2 |
| Derwentside | 3 | 12 | 1 | 12 | 1 | 7 | 0 | 5 | 1.2 | 7.9 | 3.0 | 0.0 | 5.6 | 1.9 |
| Durham | 7 | 4 | 5 | 3 | 3 | 2 | 3 | 2 | 3.7 | 2.5 | 3.9 | 3.7 | 2.5 | 3.5 |
| Chester le Street | 1 | 6 | 1 | 5 | 1 | 4 | 1 | 2 | 1.8 | 7.4 | 5.6 | 1.8 | 3.7 | 4.4 |
| Easington | 8 | 10 | 8 | 10 | 6 | 7 | 6 | 6 | 6.0 | 7.5 | 4.5 | 6.0 | 6.5 | 4.2 |
| Sedgefield | 9 | 6 | 9 | 5 | 6 | 2 | 5 | 2 | 6.7 | 2.0 | 4.7 | 5.6 | 2.0 | 3.6 |
| Teesdale | 0 | 3 | 0 | 3 | 0 | 2 | 0 | 2 | 0.0 | 10.5 | 3.5 | 0.0 | 10.5 | 5.3 |
| Sunderland | 25 | 22 | 23 | 19 | 18 | 14 | 14 | 12 | 6.1 | 4.6 | 5.2 | 4.8 | 4.0 | 4.2 |
| South Tyneside | 11 | 11 | 9 | 11 | 8 | 10 | 7 | 10 | 5.4 | 6.5 | 6.2 | 4.7 | 6.5 | 5.3 |
| Gateshead | 14 | 19 | 13 | 18 | 10 | 11 | 7 | 11 | 4.9 | 5.4 | 5.8 | 3.5 | 5.4 | 4.8 |
| North Tyneside | 17 | 14 | 15 | 12 | 12 | 9 | 10 | 9 | 5.8 | 4.3 | 4.4 | 4.9 | 4.3 | 3.7 |
| Newcastle | 32 | 25 | 29 | 22 | 20 | 16 | 19 | 9 | 6.7 | 5.5 | 5.7 | 6.4 | 3.1 | 4.3 |
| Northumberland | 27 | 21 | 22 | 19 | 13 | 11 | 12 | 5 | 5.1 | 3.7 | 4.9 | 4.5 | 1.7 | 3.9 |
| Allerdale | 6 | 4 | 5 | 4 | 2 | 2 | 2 | 1 | 2.4 | 2.2 | 2.3 | 2.4 | 1.1 | 1.9 |
| Carlisle | 9 | 7 | 8 | 6 | 5 | 5 | 5 | 5 | 4.8 | 4.5 | 4.9 | 4.8 | 4.5 | 4.9 |
| Copeland | 9 | 9 | 9 | 8 | 7 | 5 | 6 | 5 | 10.6 | 7.2 | 7.4 | 9.0 | 7.2 | 6.4 |
| Eden | 2 | 6 | 2 | 5 | 1 | 3 | 1 | 3 | 2.4 | 6.3 | 6.4 | 2.4 | 6.3 | 5.0 |
| **NORTHERN REGION** | 248 | 243 | 221 | 217 | 156 | 143 | 129 | 114 | 5.2 | 4.7 | 4.9 | 4.3 | 3.8 | 4.0 |

## Table 2.3: Northern Region 2002 & 2003: Timing of death and perinatal mortality rate (PNMR) by unit

- Registered birth data are provided by individual units.
- The table gives the total numbers of stillbirths and neonatal deaths of babies delivered at the named unit regardless of the place of booking. *Non adjusted* perinatal mortality rates are calculated using these figures.
- The figures in brackets are those babies either originally booked elsewhere but delivered in the unit (i.e., transferred either antenatally or intrapartum) or unbooked. The *adjusted* perinatal mortality rate is the rate for those babies booked and delivered at a given unit.
- Direct comparisons cannot be made between units because of the small number of deaths in any given unit.
- Totals are not identical to those in other tables as they include a few "non resident" births.

| Maternity Units | Registered Births | | Stillbirths | | ENND | | LND | | Non-Adjusted PNMR | | Adjusted PNMR | | Adjusted PNMR |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2001-2003 |
| Hartlepool | 1596 | 1600 | 11 | 8 | 1 | 5 | 0 | 0 | 7.5 | 8.1 | 7.5 | 8.1 | 6.9 |
| North Tees* | 2002 | 2067 | 10 (1) | 14(3) | 2 | 6(1) | 2(1) | 1 | 6.0 | 9.7 | 5.5 | 7.7 | 7.4 |
| James Cook | 3394 | 3560 | 20 | 17 | 9(4) | 9(1) | 5(1) | 6 | 8.3 | 7.3 | 7.2 | 7.0 | 7.8 |
| Carlisle | 1500 | 1587 | 10 | 9(1) | 0 | 2(1) | 0 | 3(1) | 7.7 | 6.9 | 6.7 | 5.7 | 6.0 |
| Whitehaven | 1183 | 1224 | 8 | 6 | 0 | 4 | 0 | 1 | 6.8 | 8.2 | 6.8 | 8.2 | 6.4 |
| Penrith | 153 | 137 | 0 | 2(2) | 0 | 0 | 0 | 0 | 0.0 | 14.6 | 0.0 | 0.0 | 4.9 |
| Darlington | 1338 | 1370 | 4 | 6 | 2 | 1 | 0 | 0 | 4.5 | 5.1 | 4.5 | 5.1 | 5.7 |
| B. Auckland | 1350 | 1387 | 12 (1) | 8 | 3 | 4 | 0 | 1 | 11.1 | 8.7 | 10.3 | 8.7 | 8.2 |
| Uni Hospital N. Durham | 2128 | 2230 | 5 | 12 | 1 | 1 | 0 | 2 | 2.8 | 5.8 | 2.8 | 5.8 | 4.2 |
| Sunderland | 3045 | 3094 | 16 | 16(1) | 9 (4) | 8(2) | 7(1) | 3 | 8.2 | 7.8 | 6.9 | 6.8 | 7.0 |
| S. Tyneside | 1395 | 1494 | 7 (2) | 7(1) | 2 | 2 | 0 | 2 | 6.4 | 6.0 | 5.0 | 5.4 | 7.1 |
| Gateshead | 1571 | 1620 | 11 | 7 | 4 | 5 | 0 | 3 | 9.5 | 7.4 | 9.5 | 7.4 | 7.9 |
| N. Tyneside | 1650 | 1725 | 8 | 4(1) | 5 | 1 | 1 | 0 | 7.9 | 2.9 | 7.9 | 2.3 | 4.4 |
| Newcastle | 4772 | 4859 | 48(12) | 40 (9) | 20(12) | 15(7) | 7(3) | 4(2) | 14.2 | 11.3 | 9.2 | 8.0 | 7.9 |
| Ashington | 1710 | 1818 | 7 (1) | 11(3) | 3 | 5 | 0 | 0 | 5.8 | 8.8 | 5.3 | 7.2 | 6.4 |
| Berwick | 52 | 31 | 0 | 0 | 0 | 0 | 0 | 0 | 0.0 | 0.0 | 0.0 | 0.0 | 6.8 |
| Alnwick | 79 | 60 | 0 | 0 | 0 | 0 | 0 | 0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Hexham | 662 | 420 | 2 | 1 | 1(1) | 0 | 0 | 1 | 4.5 | 2.4 | 3.0 | 2.4 | 2.3 |
| **Totals** | **29580** | **30283** | **182** | **168** | **65** | **68** | **23** | **27** | | | | | |

* The adjusted PNMR for North Tees, 2000-2002 given in last year's report was incorrect. The correct figure is 6.4 (adjusted PNMR, North Tees, 2000-2002).

Table 2.4: Northern Region : Timing of death by Local Authority 2002 & 2003. Infant Mortality rate by Local Authority 2002 & 2003 and for 2001-2003

| Local Authority | Registered Total Births (ONS) | | Late Abortions* | | Stillbirths | | Early Neonatal Deaths (0-6d) | | Late Neonatal Deaths (7-27d) | | Post Neonatal Deaths (28-365d) | | INFANT MORTALITY RATE | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 01/03 |
| Hartlepool | 1016 | 1067 | 3 | 6 | 7 | 2 | 3 | 5 | 0 | 0 | 2 | 2 | 4.9 | 6.6 | 5.4 |
| Stockton on Tees | 2021 | 2127 | 8 | 13 | 7 | 13 | 5 | 7 | 1 | 2 | 2 | 3 | **4.0 | 5.7 | 5.4 |
| Middlesbrough | 1707 | 1795 | 6 | 9 | 11 | 10 | 6 | 4 | 1 | 5 | 8 | 1 | 8.8 | 5.6 | 7.6 |
| Redcar & Cleveland | 1365 | 1454 | 4 | 8 | 9 | 7 | 0 | 4 | 3 | 1 | 1 | 5 | 2.9 | 6.9 | 4.7 |
| Darlington | 1143 | 1184 | 4 | 4 | 6 | 5 | 2 | 1 | 0 | 0 | 1 | 4 | 2.6 | 4.2 | 4.7 |
| Wear Valley | 654 | 642 | 1 | 2 | 7 | 3 | 5 | 3 | 0 | 0 | 1 | 0 | 9.2 | 4.7 | 7.3 |
| Derwentside | 842 | 886 | 2 | 1 | 2 | 9 | 1 | 3 | 0 | 0 | 0 | 1 | 1.2 | 4.6 | 3.8 |
| Durham | 804 | 794 | 3 | 2 | 3 | 4 | 4 | 0 | 1 | 3 | 1 | 0 | 7.5 | 3.8 | 7.5 |
| Chester le Street | 552 | 544 | 2 | 1 | 1 | 4 | 0 | 2 | 0 | 0 | 1 | 0 | 1.8 | 3.7 | 3.7 |
| Easington | 994 | 928 | 4 | 3 | 7 | 7 | 1 | 3 | 1 | 0 | 2 | 2 | 4.0 | 5.4 | 4.9 |
| Sedgefield | 899 | 978 | 0 | 6 | 7 | 4 | 2 | 2 | 0 | 1 | 3 | 3 | 5.6 | 6.1 | 6.4 |
| Teesdale | 185 | 191 | 1 | 0 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 0.0 | 0.0 | 3.6 |
| Sunderland | 2947 | 3026 | 19 | 18 | 19 | 14 | 6 | 8 | 8 | 3 | 2 | 9 | 5.4 | 6.6 | 5.5 |
| South Tyneside | 1474 | 1531 | 9 | 3 | 8 | 9 | 3 | 2 | 1 | 2 | 2 | 1 | 4.1 | 3.3 | 4.9 |
| Gateshead | 2023 | 2031 | 6 | 7 | 11 | 12 | 3 | 7 | 2 | 3 | 1 | 4 | 3.0 | 6.9 | 4.3 |
| North Tyneside | 2053 | 2114 | 11 | 16 | 13 | 12 | 4 | 2 | 0 | 0 | 6 | 5 | 4.9 | 3.3 | 4.4 |
| Newcastle | 2963 | 2913 | 13 | 20 | 24 | 19 | 8 | 6 | 3 | 3 | 4 | 4 | 5.1 | 4.5 | 4.7 |
| Northumberland | 2781 | 2950 | 7 | 12 | 19 | 15 | 8 | 6 | 2 | 1 | 4 | 2 | 4.0 | 3.1 | 3.4 |
| Allerdale | 847 | 902 | 1 | 4 | 6 | 3 | 0 | 1 | 0 | 0 | 0 | 2 | 0.0 | 3.3 | 1.8 |
| Carlisle | 1044 | 1100 | 3 | 5 | 8 | 5 | 1 | 2 | 0 | 2 | 4 | 3 | 4.8 | 6.4 | 4.5 |
| Copeland | 663 | 696 | 3 | 7 | 6 | 5 | 3 | 4 | 0 | 2 | 0 | 1 | 4.5 | 10.1 | 6.9 |
| Eden | 414 | 476 | 2 | 1 | 2 | 6 | 0 | 0 | 0 | 1 | 0 | 1 | 0.0 | 4.2 | 2.8 |
| **Northern Region** | **29394** | **30329** | **112** | **148** | **183** | **171** | **65** | **72** | **23** | **29** | **45** | **53** | **4.5** | **5.1** | **5.0** |

NOTES: *20-23 week TOP and late fetal loss; ** Changed from previous report due to late notified infant death.

Table 2.5: Northern Region. Immediate cause of Perinatal and Infant Death, infant and perinatal mortality rates 2001-2003

| | PERINATAL MORTALITY | | INFANT MORTALITY | |
|---|---|---|---|---|
| **CAUSE OF DEATH** | **Deaths 2003** | **Average rate 2001-2003** | **Deaths 2003** | **Average rate 2001-2003** |
| Malformation | 47 | 1.4 | 43 | 1.4 |
| Antepartum death (unexplained) | 100 | 3.6 | 0 | 0.0 |
| Intrapartum anoxia/trauma | 23 | 0.9 | 12 | 0.4 |
| Immaturity | 31 | 0.9 | 40 | 1.2 |
| Infection (including NEC*) | 17 | 0.6 | 27 | 1.0 |
| SIDS** | 0 | 0.0 | 13 | 0.5 |
| Accident-non IP trauma | 0 | 0.0 | 4 | 0.04 |
| Other specific causes | 22 | 0.6 | 11 | 0.3 |
| Unclassifiable | 3 | 0.03 | 4 | 0.03 |
| **All Causes** | **243** | **8.1** | **154** | **4.9** |

NOTES: *NEC – necrotising enterocolitis
**SIDS – Sudden Infant Death Syndrome

# 3. THE IMPORTANCE OF AUTOPSY

## Post mortem findings in the stillborn infant

As table 2.5 shows, unexpected stillbirth remains a common cause of perinatal death. Unfortunately there is still a misplaced perception that post mortem examination in these cases will be unhelpful, and this has undoubtedly contributed to the declining post mortem rate for this group of perinatal deaths. Numerous studies over the years have demonstrated the value of the autopsy following stillbirth, and a review of recent cases confirms that this is true for our own population.

During 2000 and 2001, 112 stillborn infants had a post mortem examination at the RVI, Newcastle. Fifteen of these cases were late terminations of pregnancy for antenatally diagnosed malformation and were excluded, leaving 97 cases. The post mortem findings were reviewed with the clinical history, and cases allocated to one of three groups:

I. **Post mortem confirmed a firm clinical diagnosis**: 22 cases (23%). Included:
   - well-grown unexplained late stillbirths;
   - cases of abruption.

II. **Provisional clinical diagnosis confirmed; or, unexpected clinically important findings which were not relevant to the death**: 21 cases (21%). Included:
   - suspected causes of hypoxia, infection or IUGR confirmed or excluded;
   - pathology of twinning;
   - investigation of suspected causes of hydrops.

III. **Unexpected and/or undiagnosed conditions causing death or with relevance for future pregnancie**s: 54 cases (56%). Included:
   - undiagnosed IUGR (29 cases) – including 3 cases of villitis;
   - unexpected cause of hypoxia (9 cases) - e.g., cord thrombosis;
   - unsuspected infection (7 cases) – including Group B Streptococcus and Cytomegalovirus (CMV);
   - undiagnosed malformations (5 cases) – e.g., tuberous sclerosis.

Unsuspected disorders were demonstrated in over 50% of cases coming to autopsy. Use of the blanket term stillbirth obscures the fact that this group of babies are dying from a variety of conditions, and post mortem highlights the need to identify antenatally those babies with potentially preventable causes. For example, over a quarter of the babies in our study had undiagnosed IUGR, a finding of major relevance with regard to monitoring of future pregnancies. Infection remains a significant cause of unexpected stillbirth. It is also worth noting that within groups I and II, malformation, infection or growth restriction could only be definitively excluded after the post mortem was completed.

**Post mortem examination will give useful information in 100% of cases**. This applies to all perinatal autopsies, not only stillbirths.

Table 3.1: Autopsy rates by unit

| UNIT | ALL DEATHS | | | | | | | | PERINATAL DEATHS | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | No. of Deaths | | No. of Post Mortems | | Post Mortem Rate (%) | | | | No. of Deaths | | No. of Post Mortems | | Post Mortem Rate (%) | | | |
| | 2002 | 2003 | 2002 | 2003 | 2000 | 2001 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2000 | 2001 | 2002 | 2003 |
| Hartlepool | 21 | 23 | 14 | 10 | 48 | 52 | 67 | 44 | 12 | 13 | 8 | 6 | 42 | 50 | 67 | 46 |
| North Tees | 27 | 35 | 8 | 17 | 33 | 40 | 30 | 49 | 12 | 20 | 3 | 12 | 14 | 44 | 25 | 60 |
| James Cook | 52 | 54 | 22 | 19 | 49 | 40 | 42 | 35 | 29 | 26 | 11 | 4 | 54 | 37 | 38 | 15 |
| Carlisle | 19 | 26 | 4 | 14 | 40 | 42 | 21 | 54 | 10 | 11 | 3 | 4 | 45 | 62 | 30 | 36 |
| West Cumberland | 10 | 24 | 8 | 9 | 53 | 36 | 80 | 38 | 8 | 10 | 6 | 4 | 70 | 20 | 75 | 40 |
| Darlington | 10 | 16 | 6 | 10 | 36 | 83 | 60 | 63 | 6 | 7 | 3 | 4 | 36 | 89 | 50 | 57 |
| Durham | 14 | 20 | 11 | 7 | 38 | 54 | 79 | 35 | 6 | 13 | 5 | 4 | 41 | 50 | 83 | 31 |
| Bishop Auckland | 21 | 19 | 6 | 3 | 72 | 65 | 29 | 16 | 15 | 12 | 2 | 2 | 73 | 62 | 13 | 17 |
| Ashington/Wansbeck | 16 | 23 | 6 | 11 | 53 | 64 | 37 | 48 | 10 | 16 | 3 | 7 | 36 | 58 | 30 | 44 |
| Hexham | 5 | 2 | 1 | 1 | 67 | 50 | 20 | 50 | 3 | 1 | 0 | 1 | 100 | 0 | 0 | 100 |
| Gateshead | 24 | 24 | 11 | 16 | 53 | 52 | 46 | 67 | 15 | 12 | 6 | 9 | 69 | 33 | 40 | 75 |
| RVI Newcastle | 107 | 103 | 56 | 45 | 62 | 61 | 52 | 44 | 68 | 55 | 34 | 26 | 63 | 60 | 50 | 47 |
| North Tyneside | 24 | 19 | 12 | 11 | 36 | 67 | 50 | 58 | 13 | 5 | 6 | 4 | 33 | 80 | 46 | 80 |
| South Tyneside | 18 | 15 | 13 | 11 | 68 | 56 | 72 | 73 | 9 | 9 | 5 | 7 | 71 | 67 | 56 | 78 |
| Sunderland | 49 | 52 | 26 | 39 | 69 | 61 | 53 | 75 | 25 | 24 | 14 | 16 | 62 | 44 | 56 | 67 |
| Home | 2 | 6 | 1 | 4 | 70 | 50 | 50 | 67 | 1 | 3 | 0 | 2 | 57 | 75 | 0 | 67 |
| Out of Region | 2 | 6 | 0 | 1 | 33 | 0 | 0 | 17 | 1 | 1 | 0 | 0 | 33 | 0 | 0 | 0 |
| **TOTALS** | **423** | **467** | **205** | **228** | **54** | **54** | **49** | **49** | **244** | **238** | **109** | **112** | **53** | **51** | **45** | **46** |

## Post mortem rates

Post mortem rates for the region and for individual units are presented in table 3.1. The numbers and rates are calculated from the numbers of deaths within a unit. There is a marked variation in rates between units with one unit having a perinatal post mortem rate of only 15%.

Overall, post-mortem rates for 2003 are similar to those for 2002. However, during 2003 there was a reverse in the marked decline in neonatal and post neonatal post mortem rates observed during 2002 (table 3.2).

Table 3.2: Autopsy rates as a percentage of all deaths by timing of death.

| | Autopsy rates (%) | | | | | | |
|---|---|---|---|---|---|---|---|
| | **Antepartum stillbirth** | **Intrapartum stillbirth** | **All stillbirth** | **Early NND** | **Late NND** | **All NND** | **Post NND** |
| 2001 | 58 | 47 | 57 | 41 | 48 | 43 | 58 |
| 2002 | 54 | 16 | 50 | 23 | 37 | 27 | 43 |
| 2003 | 50 | 50 | 50 | 37 | 39 | 37 | 59 |

# 4. SUDDEN UNEXPECTED DEATH IN INFANCY

## Sudden Unexpected Death in Infancy – "the Kennedy Report"

The Multi-professional Working Party on the investigation of Sudden Death in Infancy, chaired by Baroness Helena Kennedy QC, produced a short report, with recommendations, and a rather longer multi-agency protocol. It can be viewed, and bought, through the Royal College of Pathologists website at http://www.rcpath.org

The main issues that Kennedy addresses are:

- Initial contact and data collection;
- Death scene investigation: who, when and what;
- Roles of local paediatricians;
- Pathology issues;
- Multi-professional case discussions – involvement of Coroner & relationship with Inquests;
- Support and feedback for parents.

There are also over-arching issues such as audit and training. Although Kennedy calls for the protocol to be made "compulsory", this would presumably only be enforceable through legislation, and there will first need to be agreement that it is workable. Although the working party was convened by the Royal College of Pathologists and the Royal College of Paediatrics and Child Health (RCPCH), the Council of the RCPCH has already expressed reservations about the practicality of implementing the Kennedy report as it stands.

In the face of this uncertainty, there is much to be said for being pro-active across the North of England with a view to sharing practice, deciding on important issues such as audit, and creating a framework with which the relevant parties can feel comfortable. If we do not end up implementing Kennedy exactly to the letter, it is important that we stand together in a system that works for us. The principal stakeholders in this process are the child health services, the police service, and the coroners. Social services will be involved where child protection issues arise either under section 17 or 47 of the Children Act (1989). Longer term, all arrangements for dealing with child deaths are likely to change.

## The role of the RMSO

The context for the involvement of the RMSO is:

- We have been collecting data on all deaths from 20 weeks of gestation until the end of the first postnatal year since 1982;
- We in the Northern Region participated in the landmark study of Sudden Unexpected Deaths in Infancy (the CESDI/SUDI study) in the mid 1990s; and

- The RMSO is the agent for the Confidential Enquiry into Maternal and Child Health (CEMACH) for the Northern Region. Collating and auditing data on SUDI for the region should thus be a core business of the RMSO.

The RMSO has a clear role in audit, but individual Trusts (perhaps coming together collectively for the purpose), and the partner agencies, have the responsibility for training.

The RMSO hosted an invitation conference for police, child health professionals and Coroners on 24th November 2004 to address the issues on which it would be good to have some agreement. The output from that meeting will be circulated to the participants, and should form the basis for implementing the recommendations, in a locally and regionally sensible fashion, over the next year. This will be linked in with the development of regional procedures at Strategic Health Authority level.

# 5. CONFIDENTIAL ENQUIRY INTO MATERNAL AND CHILD HEALTH (CEMACH)

In April 2003, the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) was merged with the Confidential Enquiry into Maternal Deaths under the umbrella of the new Confidential Enquiry into Maternal and Child Health (CEMACH). This chapter provides updates on:

- The CEMACH diabetes enquiry;
- The findings from the maternal deaths enquiry.

From April 2005 CEMACH will be managed nationally through the National Patient Safety Agency (NPSA). The RMSO has already developed a project with the NPSA, described in chapter 6.

## CEMACH Diabetes Enquiry

The diabetes programme was initiated by CESDI (now CEMACH) in 2002 with the aim of identifying all pregnant women with Type 1 and Type 2 diabetes in England, Wales, Northern Ireland and the Channel Islands. Women were notified to the CEMACH regional office and a standard data set completed and forwarded at 28 days post delivery (whatever the outcome).

Data collection via the standard data set was completed in February 2003 with a further three months allowed to ensure all data was completed in the standard data set database. Once this was agreed as being complete, the first randomisation of cases took place and regions were notified of which cases they needed to collect. Requests were sent to units for copies of the notes together with a form for completion regarding pre-pregnancy care. As well as the cases randomised, all stillbirths, neonatal deaths and malformations were to be included in the set for confidential enquiry. A further randomisation took place six months later and it is hoped that the flow of cases will ensure that meetings can be arranged well in advance.

Each confidential enquiry looks at four cases comprising of two controls, one death and one malformation. The Northern Region was allocated 20 confidential enquiries which have to be completed by November 2005. Two Chairs were appointed and each panel consists of two Obstetricians, two Diabetologists, two Diabetes Specialist Nurses, two Diabetes Specialist Midwives and the regional CEMACH Manager. We were successful in carrying out ten panel meetings in 2004 and plans are already in place to hold the next ten. The response from all professionals involved in the care of women with diabetes in pregnancy has been tremendous. We are well on target for completing the CEMACH diabetes project for our region.

## Maternal Deaths Enquiry

The 6th Report of the Confidential Enquiry into Maternal Deaths indicated that the leading overall cause of maternal death is suicide[1]. The leading cause of direct deaths is thrombosis and thromboembolism. These findings are unchanged from the previous report which reported on deaths for 1997 – 1999. Maternal mortality in the UK (13.1 per 100,000 maternities) is very low in comparison with developing countries. Of all deaths in women of childbearing age in the UK, only 1.5% of deaths are classed at maternal.

The report also highlighted that women from socially disadvantaged and ethnic minority groups were much more likely to die than women living in affluent areas. Domestic violence and substance misuse also contributed to an increased risk of maternal death.

Since the RMSO has taken over the collation of data on behalf of CEMACH for the confidential enquiry into maternal deaths, the process of notification and collection of data has much improved. In each Trust there are at least two nominated supervisors of midwives who collect the data and link to the CEMACH Regional Manager. Supervisors of midwives are now more aware of the reporting mechanisms and many late deaths, which in the past may not have been reported, are now notified and fully reported to the enquiry.

[1] CONFIDENTIAL ENQUIRY INTO MATERNAL DEATHS. (2004). *Why mothers die 2000-2002.* HMSO, London. The full report is available at: www.cemach.org.uk

# 6. NORTHERN DIABETIC PREGNANCY SURVEY

## Introduction

The Northern Diabetic Pregnancy Survey (NDPS) has been running since 1995 and has been managed from the RMSO since 1999. 2003/04 has been another productive year for the survey. Some further analysis of the data is presented in this report as well as updates on the notes proforma and work on preconception care.

The total number of pregnancies and the outcomes are shown in Table 6.1.

Table 6.1: Outcome of Diabetic Pregnancies 1995-2003

| Outcome | 1995 | 1996 | 1997 | 1998 | 1999 | 2000 | 2001 | 2002 | 2003 |
|---|---|---|---|---|---|---|---|---|---|
| Women Registered | 124 | 127 | 133 | 131 | 136 | 128 | 130 | 141 | 155 |
| Live births | 97 | 100 | 97 | 102 | 113 | 111 | 102 | 122 | 137 |
| Sp. Misc.<20 weeks gestation[1] | 19 | 23 | 28 | 20 | 20 | 13 | 20 | 18 | 14 |
| Sp. Misc.20–23$^{+6}$ weeks gestation | 0 | 1 | 3 | 0 | 0 | 0 | 0 | 0 | 0 |
| Terminations | 6 | 3 | 3 | 3 | 2 | 2 | 8 | 2 | 4 |
| Antepartum Stillbirth | 3 | 3 | 2 | 5 | 5 | 2 | 1 | 3 | 2 |
| Intrapartum Stillbirth | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 | 0 |
| Early Neonatal Death (0-6 days) | 2 | 0 | 0 | 3 | 0 | 1 | 0 | 0 | 2 |
| Late Neonatal Death (7-28 days) | 2 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 |
| Postneonatal Deaths (29-365 days) | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 1 |
| Alive at 1 year | 93 | 100 | 96 | 99 | 112 | 109 | 102 | 120 | 134 |
| Total Outcomes | 125[2] | 130[3] | 134[4] | 131 | 140[5] | 128 | 131[6] | 145[7] | 157 |
| Perinatal Mortality Rate | 50.0 | 29.1 | 30.0 | 83.3 | 42.4 | 26.5 | 9.7 | 24.0 | 28.8 |

NOTES:
1. These figures underestimate pregnancy loss <20 weeks
2. 1 set of twins (2LB)
3. 3 set twins (2LB; 2LB; 1 LB+1 SB)
4. 1 set twins (2 miscarried)
5. 4 set of twins (all LB)
6. 1 set of twins (2LB)
7. 2 sets of twins (all LB), 1 set triplets (1 LND+1 PND+1 LB)
8. 2 sets of twins (all LB)

## Outcomes of pregnancy for diabetic women in the Northern region

In the UK, approximately 1 in every 250 pregnancies occurs in a woman with pre-existing diabetes[2]. This makes diabetes the most common pre-existing medical condition complicating pregnancy in this country and this is associated with increased risks for both mother and baby. These are shown in boxes 1 and 2. In particular, women with diabetes have an increased chance of their baby having a congenital malformation, of losing the baby during pregnancy or at birth, or of the baby dying in infancy.

[2] FINLAY A et al. (2000). *Continuity of Carer during Pregnancy for Diabetic Women.* British Journal of Midwifery. 2000;8:207-214

## Box 1: Risks to the baby of diabetic pregnancy

- Congenital malformations;
- Macrosomia;
- Neonatal hypoglycaemia;
- Increased risk of:
  - Neonatal jaundice,
  - Respiratory distress syndrome, and
  - Polycythaemia.

## Box 2: Risks to the mother of diabetic pregnancy

- Increasing insulin resistance resulting in hyperglycaemia and an increased risk of diabetic ketoacidosis;
- Hypoglycaemia resulting from intensive insulin therapy;
- Progression of retinopathy;
- Progression of nephropathy;
- Increased risk of pre-eclampsia, hypertensive disease of pregnancy and placental insufficiency in women with preconception microalbuminuria;
- Damage to the birth canal resulting from macrosomia.

In 1989, the St Vincent Declaration[3] set goals and targets to improve diabetes control and reduce the disease's major complications. In relation to pregnancy, this included a goal that:

> *"the outcome of diabetic pregnancy should approximate that of the non-diabetic pregnancy."*

For people with diabetes, glycaemic control is one of the key indicators of their likelihood of developing long-term complications from the disease. Therefore the measurement and assessment of glycaemic control is fundamental to their management. HbA1c a specific form of glycated haemoglobin (the term used to describe the amount of glucose that has "stuck" to the red blood cells in the blood stream[4]) is used as a longer–term method of assessing glycaemic control. HbA1c changes slowly and is therefore measured every 3-6 months.

The Northern Diabetic Pregnancy Survey uses HbA1c as the measure for glycaemic control and categorises control as:

- Good – where HbA1c falls within the assay range;
- Moderate – where HbA1c is above the assay range and up to 8.5%; or
- Poor – where HbA1c is greater than 8.5%.

During 2003 and 2004 two projects have been undertaken to assess whether there has been progress towards meeting the St Vincent Declaration target for diabetic pregnancy. These

[3] WORLD HEALTH ORGANISATION & INTERNATIONAL DIABETES FEDERATION. (1989). *Diabetes Care and Research in Europe: the St Vincent Declaration.* Diabetic Medicine. 1990;7:360.

[4] NORTHUMBRIA DIABETES SERVICE. (2001). *Your Guide to the HbA1c Test.* Northumbria Healthcare NHS Trust.

projects focus on major outcomes for babies (infant mortality and congenital anomalies); and obstetric outcomes respectively. Both use data from other sources (e.g., ONS Link File – which links infant deaths to birth cohort data, NorCAS data, and Hospital Episode Statistics) alongside the NDPS data. Key results from the projects are reported below.

### *Outcomes for babies*

This project aimed to determine whether there has been progress towards meeting the St Vincent declaration target of diabetic pregnancy outcome approximating non-diabetic pregnancy outcome for the population of Northern England. NDPS data for the years 1995-2002 were used to compare the outcomes of diabetic pregnancy with those of all pregnancies in the region based on outcomes identified in the first year of the audit in 1994[5]. The outcome measures chosen in this study relate to the risks of diabetic pregnancy on the survival and condition of the baby:

- **Late fetal loss rate** – the number of miscarriages occurring at ≥ 20 weeks' gestation and < 24 weeks' gestation per 1,000 miscarriages, stillbirths and live births.
- **Stillbirth rate** – the number of stillborn babies per 1,000 total births (live births and stillbirths).
- **Perinatal mortality rate** – the number of stillbirths and deaths in the first seven days of life per 1,000 total births (live births and still births).
- **Neonatal mortality rate** – the number of deaths in the first 28 days of life per 1,000 live births.
- **Infant mortality rate** – the number of deaths in the first year of life per 1,000 live births.
- **Congenital malformation rate per 1,000 babies born** – the number of babies with malformations in live births and stillbirths per 1,000 total births (live and still births).

Table 6.2: Outcomes of pregnancy (rates per 1,000, odds ratios and 95% confidence intervals) for all pregnancies in the Northern Region and for diabetic pregnancies in the Northern Region 1995-2002

| | All Pregnancies | | Diabetic Pregnancies | | Odds ratio (95% CI) |
|---|---|---|---|---|---|
| | Number | Rate | Number | Rate | |
| Late fetal loss | n/a | n/a | 4 | 4.6 | n/a |
| Stillbirth | 1,449 | 5.7 | 26 | 29.9 | 5.4 (3.6, 7.9) |
| Perinatal mortality | 2,168 | 8.6 | 32 | 36.8 | 4.4 (3.1, 6.3) |
| Neonatal mortality | 948 | 3.8 | 10 | 11.8 | 3.2 (1.7, 5.9) |
| Infant mortality | 1,394 | 5.5 | 13 | 15.4 | 2.8 (1.6, 4.9) |
| Congenital malformations | 5,105 | 20.2 | 66 | 75.9 | 4.0 (3.1, 5.1) |
| **All Births** | **253,021** | **n/a** | **870** | **n/a** | **n/a** |

The results in Table 6.2 show that:

[5] HAWTHORNE GC et al. *Prospective Population Based Survey of Outcome of Pregnancy in Diabetic Women: Results of the Northern Diabetic Pregnancy Audit*. British Medical Journal. 1997;315:279-281.

- The perinatal mortality rate for diabetic pregnancies in Northern England was 36.8 per 1,000 for 1995-2002 whilst the rate for all pregnancies was 8.6 per 1,000.
- Risks for all mortality related outcomes in the Northern region are significantly higher for diabetic pregnancies than for the background population.
- The largest increase in risk for diabetic pregnancies over pregnancies in the background population is for stillbirth (5 fold increase) and the lowest is for infant death (3 fold increase). There was a 4 fold increased risk of perinatal mortality for diabetic pregnancies.
- The congenital malformation rate per 1,000 babies born for diabetic pregnancies in the Northern region was 75.9 per 1,000 for 1995-2002 whilst the rate for all pregnancies was 20.2 per 1,000.
- Risks for congenital malformation in the Northern region are significantly higher for diabetic pregnancies than for the background population.

This study also considered:

- The effect of different levels of glycaemic control 3 months pre-pregnancy and in the first trimester on the main outcomes of perinatal mortality and congenital malformation - findings are reported in Table 6.3; and
- The effect of regular fetal monitoring in trimester 3 on the outcome of perinatal mortality – findings are reported in Table 6.4.

Table 6.3: Number and percentage of births for which the mother had specified levels of control of glycated haemoglobin 3 months pre-pregnancy and in trimester 1 and the effect on perinatal mortality and congenital malformation rate, 1995-2002

| Number (%) with HbA1c control | | | Perinatal Mortality | | | | Congenital Malformations | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | No | Rate | OR [95% CI] | | No | Rate | OR [95% CI] | |
| ***3 months pre-pregnancy*** | | | | | | | | | | |
| Good | 40 | (4.6) | 3 | 75.0 | 9.4 | [2.9-30.4] | 3 | 75.0 | 3.9 | [1.2-12.8] |
| Moderate | 203 | (23.3) | 2 | 9.9 | 1.2 | [0.3-4.6] | 8 | 39.4 | 2.0 | [1.0-4.0] |
| Poor | 144 | (16.6) | 8 | 55.6 | 6.8 | [3.3-13.9] | 14 | 97.2 | 5.2 | [3.0-9.1] |
| ***Trimester 1*** | | | | | | | | | | |
| Good | 114 | (13.1) | 6 | 52.6 | 6.4 | [2.8-14.6] | 5 | 43.9 | 2.2 | [0.9-5.5] |
| Moderate | 436 | (50.1) | 11 | 25.2 | 3.0 | [1.6-5.5] | 26 | 59.6 | 3.1 | [2.1-4.6] |
| Poor | 179 | (20.6) | 10 | 55.9 | 6.8 | [3.6-13.0] | 20 | 111.7 | 6.1 | [3.8-9.7] |

Table 6.4: Number and percentage of births for which the mother had BPP weekly or CTG twice weekly from 34 weeks gestation and the effect on perinatal mortality, 1995-2001

| Number (%) with BPP weekly or CTG twice weekly from 34 weeks | | | Perinatal Mortality | | |
|---|---|---|---|---|---|
| | | | No | Rate | OR [95% CI] |
| Yes | 83 | (12.7) | 2 | 24.1 | 2.9 [0.7-11.6] |
| No | 568 | (87.3) | 12 | 21.1 | 2.5 [1.4-4.4] |

The results in Tables 6.3 and 6.4 show:

- Those with good control of glycated haemoglobin 3 months pre-pregnancy had a 4 fold increased risk of congenital malformation which was not statistically significant and a 9 fold increased risk of perinatal mortality which was statistically significant.
- Those with moderate control had congenital malformation rates and perinatal mortality rates that were not statistically different from the background population.
- Those with good control of glycated haemoglobin in trimester 1 had a 2 fold increased risk of congenital malformation and a 6 fold increased risk of perinatal mortality which were statistically significant.
- Those with moderate control had a 3 fold increased risk of both congenital malformation and perinatal mortality which were statistically significant.
- In both cases, those with poor control, had a 5-7 fold increased risk of congenital malformation and an 8 fold increased risk of perinatal mortality and fared significantly worse than the background population.
- Births to women who did have BPP weekly or CTG twice weekly from 34 weeks gestation had a perinatal mortality rate which was not statistically significantly different from the background population.
- Births to women who did not have BPP weekly or CTG twice weekly from 34 weeks gestation had a 3 fold increased risk of perinatal mortality which was statistically significant.

There is clearly still some way to go if we are to achieve the goal of the St Vincent declaration. The risks of stillbirth, perinatal mortality, neonatal mortality and infant mortality remain significantly higher for diabetic pregnancies than for pregnancies in the background population. The risks of congenital malformation also remain significantly higher for diabetic pregnancies than for pregnancies in the background population. More work is needed to clarify what degree of control will lead to the best outcomes for babies.

### *Obstetric Outcomes*

This project aimed to determine whether there has been progress towards meeting the St Vincent declaration target of diabetic pregnancy outcome approximating non-diabetic pregnancy outcome for the population of Northern England. NDPS data for the years 1995-2002 was used to look at the obstetric outcomes of singleton diabetic pregnancies.

Key outcome measures were:

- **Pre-eclampsia–** Number of births with a diagnostic code of ICD-10 O14 (gestational hypertension with significant proteinuria) from the HES data expressed as a percentage of all births from the ONS Link File;
- **Caesarean section –** Number of births with a procedure code of OPCS-4 R17 (elective caesarean delivery) or R18 (other caesarean delivery) in HES data expressed as a percentage of all births from the ONS Link File;
- **Macrosomia proxy –** Number of births with a birthweight of greater than 4000g (as a proxy for macrosomia) expressed as a percentage of all births from the ONS Link File;

- **Polyhydramnios –** Number of births with a diagnostic code of ICD-10 O40 (polyhydramnios) from the HES data expressed as a percentage of all births from the ONS Link File.

Table 6.5: Outcomes of pregnancy (percentages, odds ratios and 95% confidence intervals) for all pregnancies in the Northern Region and for diabetic pregnancies in the Northern Region 1995-2002

| | All Pregnancies | | Diabetic Pregnancies | | Odds ratio (95% CI) |
|---|---|---|---|---|---|
| | Number | % | Number | % | |
| Pre-eclampsia | 3,698 | 1.5 | 155 | 18.6 | 15.0 (12.6-17.9) |
| Caesarean section | 38,946 | 15.8 | 496 | 59.1 | 7.7 (6.7-8.8) |
| Macrosomia proxy[1] | 26,942 | 10.9 | 175 | 20.8 | 2.1 (1.8-2.5) |
| Polyhydramnios[2] | 132 | 0.2 | 17 | 7.8 | 36.7 (21.8-62.0) |
| **Singleton Births** | **246,308** | **n/a** | **841** | **n/a** | **n/a** |

NOTES:
1. Birthweight of > 4,000g is used as a proxy for macrosomia.
2. Data for polyhydramios is for 2001-2002 only.

The results in Table 6.5 show that:

- The rate of pre-eclampsia for diabetic pregnancies in Northern England was 18.6% for 1995-2002 whilst the rate for all pregnancies was 1.5%; this represents a 15 fold increased risk.
- The caesarean section rate for diabetic pregnancies in Northern England was 59.1% for 1995-2002 whilst the rate for all pregnancies was 15.8%; this represents an 8 fold increased risk.
- The percentage of births with a birthweight of greater than 4,000g for diabetic pregnancies in Northern England was 20.8% whilst the percentage for all pregnancies was 10.9%.
- The rate of polyhydramnios in diabetic pregnancies in Northern England was 7.8% for 1995-2002 whilst the rate for all pregnancies was 0.2%; this represents a 37 fold increased risk.
- Risks for pre-eclampsia, caesarean section, birthweight > 4,000g and polyhydramnios in the Northern region are significantly higher for diabetic pregnancies than for the background population.

This study also considered the effect of different levels of glycaemic control in the first trimester on the main outcomes of pre-eclampsia, caesarean section, high birthweight and polyhydramnios. Findings are reported in Table 6.6 and Table 6.7.

Table 6.6: Number and percentage of births for which the mother had specified levels of control of glycated haemoglobin in trimester 1 and the effect on pre-eclampsia, caesarean section, and high birthweight, 1995-2002

| Number (%) with HbA1c control | | | Pre-eclampsia | | |
|---|---|---|---|---|---|
| | | | No | % | OR [95% CI] |
| Good | 112 | (13.3) | 14 | 12.5 | 9.4 [5.4-16.5] |
| Moderate | 418 | (49.7) | 83 | 19.9 | 16.3 [12.8-20.8] |
| Poor | 179 | (21.3) | 37 | 20.8 | 17.2 [12.0-24.8] |
| **Number (%) with HbA1c control** | | | **Caesarean Section** | | |
| | | | **No** | **%** | **OR [95% CI]** |
| Good | 112 | (13.3) | 47 | 42.0 | 3.9 [2.6-5.6] |
| Moderate | 418 | (49.7) | 255 | 61.0 | 8.3 [6.8-10.1] |
| Poor | 179 | (21.3) | 117 | 65.4 | 10.1 [7.4-13.7] |
| **Number (%) with HbA1c control** | | | **Birthweight > 4,000g** | | |
| | | | **No** | **%** | **OR [95% CI]** |
| Good | 112 | (13.3) | 23 | 20.5 | 2.1 [1.3-3.3] |
| Moderate | 418 | (49.7) | 99 | 23.7 | 2.5 [2.0-3.2] |
| Poor | 179 | (21.3) | 25 | 14.0 | 1.3 [0.9-2.0] |

Table 6.7: Number and percentage of births for which the mother had specified levels of control of glycated haemoglobin in trimester 1 and the effect on polyhydramnios, 2001-2002

| Number (%) with HbA1c control | | | Polyhydramnios | | |
|---|---|---|---|---|---|
| | | | No | % | OR [95% CI] |
| Good | 32 | (14.7) | 0 | 0.0 | 0.0 |
| Moderate | 113 | (52.1) | 11 | 9.7 | 46.6 [24.5-88.8] |
| Poor | 45 | (20.7) | 6 | 13.3 | 66.5 [27.7-159.7] |

The results in Table 6.6 and 6.7 show that:

- Those with good control of glycated haemoglobin in trimester 1 had a 9 fold increased risk of pre-eclampsia, a 4 fold increased risk of caesarean section and a 2 fold increased risk of having a baby of high birthweight (> 4,000g) when compared to the background population – all were statistically significant.
- Those with moderate control had a 16 fold increased risk of pre-eclampsia, an 8 fold increased risk of caesarean section, a 2-3 fold increased risk of having a baby of high birthweight, and a 47 fold increased risk of polyhydramnios – all were statistically significant.
- Those with poor control had a 17 fold increased risk of pre-eclampsia, a 10 fold increased risk of caesarean section and a 67 fold increased risk of polyhydramnios – all were statistically significant.

Those with poor control had a risk of having a baby of high birthweight (> 4,000g) which was not statistically significantly different from the background population – this group were more likely than the others to have a premature delivery (OR=2.3; 95%CI 1.7-3.2 compared to all diabetics).

There is clearly still some way to go if we are to achieve the goal of the St Vincent declaration. The risks of pre-eclampsia, caesarean section, having baby of high birthweight and polyhydramnios remain significantly higher for diabetic pregnancies than for

pregnancies in the background population. Good control of glycated haemoglobin in trimester 1 relates to the best obstetric outcomes.

### *Key Messages from both projects*

The St Vincent declaration target has not been met. Diabetic pregnancy remains a high-risk state. There has been little progress in reducing the poor outcomes (such as perinatal mortality and congenital malformation rate) over the last 8 years. There is still some progress to be made in relation to meeting the agreed regional standards of care for the management of women with pre-existing diabetes who become pregnant.

- Pregnancy planning is important – work is underway to consider how to make this more effective.
- Poor glycaemic control before and during pregnancy leads to increased risks for perinatal mortality and congenital malformation and for poor obstetric outcomes.
- Regular fetal monitoring during trimester 3 may reduce perinatal mortality rates.

## Work programme

The NDPS has been very successful in "closing the audit loop" in 2003 and 2004:

- Standards of care for diabetic pregnancy were amended during 2003 as a result of the survey findings. Revised standards are now in use across the region.
- A new notes proforma was launched in October 2003.
- The survey has highlighted the need for enhanced pre pregnancy care and a meeting for PCT Diabetes Leads and Specialist Clinicians will be held in early 2005.
- The survey and pilot confidential enquiries conducted in the region informed the CEMACH diabetic pregnancy programme.

Ongoing activities include:

- CEMACH diabetic pregnancy enquiry panels are underway during 2004 and 2005.
- Work is ongoing to adopt the notes proforma across the region.
- One unit is piloting the use of the standards as part of the information to be given directly to women.

# 7. MATERNITY CARE

## Delivery statistics

The delivery statistics supplied by the individual units are shown in Table 7.1. For the second year running, the delivery rate for most units has shown a small increase. This follows a major trend of falling birth rates throughout the 1990s and suggests the birth rate may be stabilising.

Now fully reflecting service changes, three units exceed three thousand deliveries per year and a further two exceed two thousand deliveries. The three smallest units however do show significant falls in their delivery rate.

The only change shown in the table is a small increase in caesarean section rates reflecting changes in national practice. All other details collected by this survey show no significant changes from the previous reports suggesting no recent major changes in practice.

## Changes in service configuration

This year's delivery statistics should not be viewed in isolation. Trends over the previous reports suggest a differentiation between specialist and non-specialist provision of service. The three largest units now represent a tertiary care service. Referral patterns into these services are reflected in the complexity of neonatal services provided. The underlying principle of transfer of complex cases to these units is supported by evidence of good outcomes. At the other end of the scale the three smallest units, which are all Midwifery led, whilst showing a fall in delivery rates are providing an important local service for which the number of deliveries is a poor marker. They are at the centre of their communities, a resource for ante-natal care and advice and have a role in avoiding unnecessary admissions into larger units. They also offer choice for women who wish to opt for this pattern of maternity care.

For the future, it is the nature of services which will be provided in units delivering between one thousand and two thousand babies per year which represents an increasing dilemma for planners and commissioners of service. In the coming years many factors will need to be considered including: women's choice; provision of supporting services; provision of twenty-four hour services in the light of changes to working time legislation. The role of Consultant Obstetricians and the need to maintain their skills and satisfy requirements for GMC revalidation becomes complex following consultant expansion, changes in working patterns, tertiary transfer of the most complex cases and the transfer of much 'low risk' care to Midwives. The future is uncertain. Service reviews are already underway but that process appears cumbersome and slow and service pressures may well force change in advance of the planning process. A move towards a more network based system seems inevitable.

Table 7.1: Delivery Statistics supplied by units; figures in brackets are %

| Unit | Maternities | | Births | | Twins | | Breech | | Induction | | Normal vertex delivery | | Assisted | | Caesarean section | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 | 2002 | 2003 |
| Hartlepool | 1576 | 1575 | 1596 | 1600 | 20 (1.3) | 23 (1.5) | 46 (2.9) | 50 (3.2) | 305 (19.4) | 361 (22.9) | 1138 (71.3) | 1151 (73.1) | 76 (4.8) | 102 (6.5) | n/a | 318 (20.2) |
| North Tees | 1966 | 2035 | 2002 | 2067 | 32 (1.6) | 32 (1.6) | 95 (4.7) | 85 (4.2) | 414 (21) | 357 (17.5) | 1380 (69) | 1426 (70.1) | 219 (11) | 251 (12.3) | 310 (15.5) | 325 (16.0) |
| James Cook University Hospital | 3296 | 3508 | 3394 | 3560 | 92 (2.8) | 49 (1.4) | 112 (3.3) | 150 (4.3) | 931 (28.2) | 805 (22.9) | 2177 (64.1) | 2412 (68.8) | 404 (11.9) | 394 (11.2) | 639 (18.8) | 706 (20.1) |
| Cumberland Infirmary | 1472 | 1557 | 1500 | 1587 | 28 (1.9) | 30 (1.9) | 59 (3.9) | 63 (4.0) | 337 (22.9) | 282 (18.1) | 1075 (71.7) | 1327 (85.2) | 80 (5.3) | 101 (6.5) | 354 (23.6) | 278 (17.9) |
| W. Cumberland Infirmary | 1163 | 1204 | 1183 | 1224 | 20 (1.7) | 20 (1.7) | 38 (3.2) | 47 (3.9) | n/a | 277 (23.0) | 854 (72.2) | 864 (71.8) | 95 (8) | 116 (9.6) | 181 (15.3) | 255 (21.2) |
| Penrith | | 137 | | 137 | | | | | | | | 137 (100) | | | | |
| Darlington | 1313 | 1358 | 1335 | 1370 | 22 (1.7) | 12 (0.9) | n/a | 13 (1.0) | 416 (32) | 382 (28.1) | 951 (71.2) | 969 (71.4) | 112 (8.4) | 109 (8.0) | 260 (19.5) | 267 (19.7) |
| B. Auckland | 1323 | 1376 | 1336 | 1387 | 13 (1) | 18 (1.3) | n/a | 6 (0.4) | 245 (18.5) | 270 (19.6) | 929 (70) | 972 (70.6) | 127 (9.5) | 134 (9.7) | 274 (20.5) | 264 (19.2) |
| University Hospital of North Durham | 2105 | 2239 | 2125 | 2230 | 23 (1.1) | 32 (1.4) | 20 (1) | 41 (1.8) | 484 (23) | 527 (23.5) | 1491 (70.1) | 1508 (67.4) | 194 (9.1) | 243 (10.9) | 432 (20.3) | 440 (19.7) |
| Sunderland | 3030 | 3090 | 3073 | 3094 | 37 (1.2) | 35 (1.1) | 117 (3.8) | 103 (3.3) | 517 (17.1) | 492 (15.9) | 2125 (69.2) | 2060 (66.7) | 405 (13.2) | 400 (12.9) | 373 (12.1) | 455 (14.7) |
| S. Tyneside | 1368 | 1476 | 1395 | 1494 | 27 (2) | 16 (1.1) | 54 (3.9) | 61 (4.1) | 294 (21) | 373 (25.3) | 964 (69.1) | 1045 (70.8) | 140 (10) | 147 (10.0) | 262 (18.8) | 249 (16.9) |
| Gateshead | 1545 | 1590 | 1571 | 1620 | 26 (1.7) | 27 (1.7) | 62 (4) | 53 (3.3) | 305 (19.7) | 332 (20.9) | 1126 (71.7) | 1055 (66.4) | 93 (5.9) | 187 (11.8) | 290 (18.5) | 292 (18.4) |
| N. Tyneside | 1641 | 1707 | 1662 | 1725 | 19 (1.2) | 18 (1.1) | 75 (4.5) | 62 (3.6) | 340 (20.7) | 319 (18.7) | 1176 (70.8) | 1324 (77.6) | 131 (7.9) | 120 (7.0) | 265 (15.9) | 300 (17.6) |
| Wansbeck | 1688 | 1793 | 1711 | 1818 | 21 (1.2) | 25 (1.4) | 83 (4.9) | 72 (4.0) | 346 (20.5) | 377 (21.0) | 1032 (60.3) | 1025 (57.2) | 231 (13.5) | 305 (17.0) | 351 (20.5) | 403 (22.5) |
| Berwick | 52 | 31 | 52 | 31 | | | | | | | 52 (100) | 31 (100 | | | | |
| Alnwick | 79 | 60 | 79 | 60 | | | | | | | 79 (100) | 60 (100) | | | | |
| Hexham | 662 | 416 | 670 | 420 | 8 (1.2) | 5 (1.2) | 14 (2.1) | 15 (3.6) | 165 (24.9) | 55 (13.2) | n/a | 297 (71.4) | 58 (8.7) | 25 (6.0) | 115 (17.2) | 82 (19.7) |
| Newcastle RVI | 4662 | 4765 | 4781 | 4859 | 110 (2.4) | 86 (1.8) | 166 (3.5) | 164 (3.4) | 775 (16.6) | 970 (20.4) | 2946 (61.6) | 2954 (62.0) | 820 (17.2) | 846 (17.8) | 844 (17.7) | 926 (19.4) |
| **Total** | 29172 | 29917 | 29697 | 30283 | 498 | 428 | 889 | 985 | 5874 | 6179 | 20372 | 20617 | 3185 | 3480 | 4950 | 5560 |

# 8. MATERNAL MORBIDITY

## Introduction

This chapter covers two aspects of maternal morbidity:

- A project with the National Patient Safety Agency (NPSA) to compare approaches to the investigation of "near misses";
- The impact of maternal obesity on pregnancy outcomes and resulting issues for midwifery practice.

## NPSA Project

The RMSO approached the National Patient Safety Agency in 2003 to propose some collaborative work on the two modes of inquiry that are prominent in health care at the moment. These are critical incident review using root cause analysis and confidential enquiries, as used by the Confidential Enquiry into Maternal and Child Health (formerly CESDI, now CEMACH).

Participants in Confidential Enquiry panels in this region have valued them as an educational exercise as well as for the output in identifying issues of sub-optimal care that need to be rectified[6]. However they are always limited by the fact that the deliberations of the panel are confined to the paper record and cannot take into account the recollections of professionals involved with the events.

In contrast, critical incident reviews have the advantage of the participation of the professionals closest to the events as well as the written records, but the potential disadvantage is that there is less objective scrutiny by persons outwith the local service.

It is therefore likely that the two modes of inquiry will yield different angles on any given event, and it is important both to the NPSA, under which CEMACH now sits, and to the wider health community, to understand how these approaches differ and therefore which may be most appropriate for which kinds of enquiry.

The RMSO is therefore collaborating with the NPSA, who are funding the project, to apply both techniques to a series of events. First, using the Maternal Morbidity Register (events collected by the RMSO from 1998 to August 2003), both techniques will be applied to events retrospectively and in the usual anonymised format. Then, in collaboration with the Directorate of Women's Services at the RVI in Newcastle, events identified prospectively will be analysed as critical incident reviews using root cause analysis as part of the routine risk management approach within the Trust. The case notes will then be anonymised and subjected shortly afterwards to confidential enquiry using an independent multidisciplinary panel in the usual way.

Analysis will focus on whether each technique results in the identification of similar or different issues, and the weight given to them by each approach. This will further be

[6] RANKIN J, BUSH J, CRESSWELL P, BELL R, RENWICK M, WARD-PLATT M. Changing practice: the impact of CESDI in the North of England. In: *Adverse outcomes in maternity care–recommendations from the Confidential Enquiries*. CEMACH, 2003. Pages 137-150.

analysed according to whether events are examined retrospectively or prospectively. The results will be important to the NPSA, the confidential enquiries, and practitioners in maternity services.

## Obesity

Obesity is a growing problem world wide. The World Health Organisation (WHO) describes it as a "global epidemic" threatening both western industrialised countries and others in the developing world[7]. This has a large impact on health care as obesity is associated with an increased risk of mortality at all ages. It is now reported that in England 24% of adult women are obese with a further 33% being overweight[8].

Definitions of what is considered obese vary. For adults in England obesity is defined as having a BMI of over 30, with morbid obesity being a BMI of over 35 (Table 8.1).

Table 8.1: Classification of obesity and malnutrition according to BMI

| Classification | BMI kg/m$^2$ |
|---|---|
| Obese Class 3 | >40 |
| Obese Class 2 | 35.0 – 39.9 |
| Obese Class 1 | 30.0 – 34.9 |
| Overweight | 25.0 – 29.9 |
| Normal weight | 18.5 – 24.9 |
| Underweight | <18.5 |

*Source World Health organisation, 2001*

In the United States the Surgeon General has made a call for action on obesity with particular focus being placed upon risks associated with pregnancy. The risks include increased risk of morbidity and mortality for both mother and baby[9].

### *What it means for midwifery practice*

The 6th Report on the Confidential Enquiry into Maternal Deaths (CEMD) in the United Kingdom[10] indicated that 35% of women who died were obese; 50% more than in the general population. The leading cause of direct maternal deaths was pulmonary thromboembolism (PTE) and the enquiry demonstrated an association between obesity and maternal death particularly with PTE. However maternal obesity was also noted to be present with many of the other deaths reported within the enquiry and this supports evidence from other countries that maternal obesity is associated with a higher risk of maternal morbidity and mortality. The CEMD report also highlighted that women in lower social classes and disadvantaged groups had an increased risk of morbidity and mortality. It

[7] WHO (2001) *Obesity: preventing and managing the global epidemic. Report of a WHO Consultation on Obesity.* WHO, Geneva.

[8] NATIONAL AUDIT OFFICE (2001) *Tackling Obesity in Britain.* HMSO, London.

[9] www.surgeongeneral.gov/topics/obesity/calltoaction/fact_consequences.htm.

[10] CONFIDENTIAL ENQUIRY INTO MATERNAL DEATHS. (2004). *Why mothers die 2002 2006.* HMSO, London.

is recognised that obesity is commoner in less affluent populations, thus increasing the risk of maternal mortality and morbidity in an already at risk population[11].

Obese women have up to five times greater risk of developing pre-eclampsia and are twice as likely to have labour induced or to have a caesarean section[12].

Studies from other countries indicate that babies born to women who are obese are two to three times more likely to be stillborn or die in the neonatal period when compared with normal weight women[12]. Overweight and obese women are more likely to have babies with congenital abnormalities than women of normal weight[13].

Antenatal care

The 6th Report on the Confidential Enquiry into Maternal Deaths in the United Kingdom recommends that BMI must be calculated for all women at booking and that midwives must also give advice on weight reduction and healthy eating with referral to a dietician and advice on exercise as appropriate.

Intrapartum care

Care in labour may be challenging as the woman is more likely to require an operative delivery and runs an increased risk of shoulder dystocia. In addition there are major equipment implications in caring for women who are obese. Specialised delivery beds, theatre tables and hoists which can cope with the weight need to be available. Larger wheel chairs are also needed as standard ones are unsuitable for obese women. Accommodation has to be to fit for purpose and many modern bathroom facilities may not be suitable for use by obese women e.g., wall hung toilets and shower seats are unable to cope with the weight.

Post partum care

Maternal obesity has also been linked with a shorter duration of breast feeding and failure to maintain adequate lactation. The Journal of Human Lactation (2004) recommends that extra help and support is required for mothers who are obese if they are to initiate and maintain breastfeeding[14].

[11] PRESCOTT-CLARKE P, PRIMATESTA P (EDS) (1998) *Health Survey for England 1996*. HMSO, London.

[12] SEBINE N, JOLLY M, HARRIS P, WADSWORTH J et al. Maternal obesity and pregnancy outcome: a study of 287213 pregnancies in London. International Journal of Obesity 2001; 25:1175-82.

[13] CEDERGREN MI, KALLEN BAJ. (2003). *Maternal Obesity and Infant Heart Defects.* Obesity Research. 2003;11:1065-1071.

[14] JOURNAL OF HUMAN LACTATION. (2004). *Research to Practice*. Journal of Human Lactation. 2004:20(2);252-254.

## Collecting BMI data at the RMSO

Maternal height and weight data started to be collected with reasonable consistency in 1993. Tables 8.1 and 8.2 refer to the cases on the RMSO database with dates of birth 1993-2003 inclusive. NorCAS was the last survey to add BMI to the survey form, this occurred in 2004. This explains the low percentage of NorCAS cases (10.1%) for which maternal BMI is completed. Improving BMI coverage is one of the RMSO targets for 2005.

Table 8.2. BMI coverage 1993-2003 for each survey (multiple births by number of pregnancies, not the total number of births).

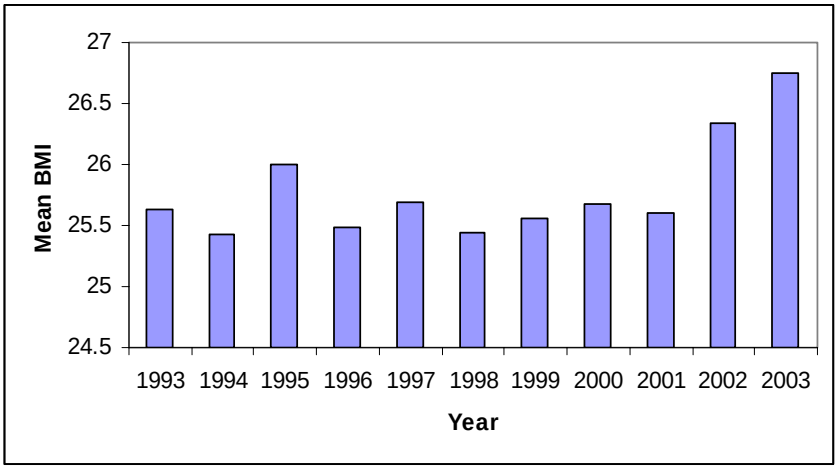
| Survey | Total cases | BMI recorded | Percentage cover |
|---|---|---|---|
| Diabetes | 1308 | 894 | 68.3 |
| NorCAS | 10325 | 1039 | 10.1 |
| Perinatal mortality | 6118 | 3196 | 52.2 |
| Multiple births | 3196 | 1519 | 47.5 |

Table 8.3: BMI coverage by year 1993-2003 for the surveys.

| Year | Total cases | BMI recorded | Percentage cover |
|---|---|---|---|
| 1993 | 1609 | 512 | 31.8 |
| 1994 | 1612 | 531 | 32.9 |
| 1995 | 1589 | 338 | 21.3 |
| 1996 | 1657 | 455 | 27.5 |
| 1997 | 1594 | 441 | 27.7 |
| 1998 | 2423 | 623 | 25.7 |
| 1999 | 2337 | 636 | 27.2 |
| 2000 | 2232 | 690 | 30.9 |
| 2001 | 2018 | 799 | 39.6 |
| 2002 | 2156 | 880 | 40.8 |
| 2003 | 1992 | 762 | 38.3 |

Figure 8.1 shows mean BMI over this period, with an upward trend apparent.

Figure 8.1: Mean BMI of mothers by year 1993-2003



# 9. NEONATAL INTENSIVE CARE

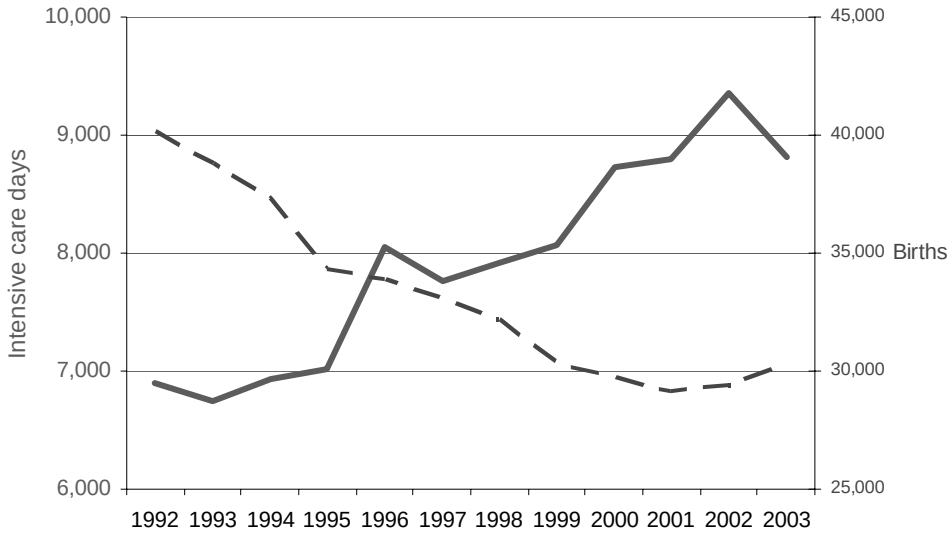
## Neonatal Intensive Care Review

In April 2003 the Department of Health published its report of the Expert Working Group on Neonatal Intensive Care (NIC) services, which concluded that the current delivery of neonatal care is not sustainable[15]. The review considered the options for NIC configurations, and came down in favour of Managed Clinical Networks as the appropriate service model.

The neonatal consortium for the North of England is an established Managed Clinical Network, and has been functioning as such since 1992. However in the light of the national review, the consortium began reviewing the regional intensive care provision in July 2002. This report summarises the full review document which was produced in February 2004.

Cot occupancy and activity have been monitored on a daily basis since 1992. Over this period there has been an inexorable increase in the intensive care workload (number of occupied intensive care cot days per year), from 6,899 (1992) to 8,806 (2003) in the intensive care provider units, despite a 25% reduction in the regional birth rate (figure 9.1). This increase is mirrored in other UK tertiary centres and reflects the progressively increasing survival of small frail babies. Evidence from North America suggests that, even with a static birth rate, neonatal intensive care activity will continue to increase at 1 – 1.5% per year. The financial planning in the review assumed 1% annual activity growth, but if the birth rate continues to rise, this may prove to be an underestimate.

Figure 9.1 Intensive Care workload 1992-2003, Northern Neonatal Network




[15] DEPARTMENT OF HEALTH EXPERT WORKING GROUP. *Neonatal Intensive Care Review*. Department of Health. April 2003.

The local increase in need for intensive care is even greater than these figures suggest as evidenced by the increasing numbers of mothers and babies who have to be transferred out of region for care (32 instances involving 40 infants from Newcastle alone in 2002; 22 instances in 2003). At present, 4% of intensive care and 14% of high dependency care (short term ventilation and continuous positive airway pressure-CPAP) occurs in one of the non provider units. If these babies were to be transferred, even greater cot numbers would be required. The regional consensus is that there is no need to make major changes to this pattern of care for the medium term.

The regional review has assumed that 70% occupancy is ideal and should be sought. On this basis, and ignoring the "out of consortium" babies at Newcastle who are mostly from other regions who should now add their own extra capacity, but including the out of region babies at James Cook who are largely from north Yorkshire, we need approximately 14,000 cot days to be safe. This implies that 10 more intensive care cots are needed to meet demand and provide a safe service at an average of 70% occupancy.

Table 9.1 Activity (Intensive Care Days), 2003/04

| UNIT | TOTAL COTS | ACTIVITY CONSORTIUM | ACTIVITY OUT OF REGION | MEAN IC COT OCCUPANCY (%) |
|---|---|---|---|---|
| Newcastle | 12 | 3477 | 3606 | 82 |
| Sunderland | 4 | 1524 | 1532 | 105 |
| South Tees | 8 | 1954 | 2174 | 74 |
| North Tees | 4 | 1184 | 1232 | 84 |
| **TOTAL** | 28 | 8139 | 8544 | 84 |

The review considered the following aspects in relation to the possible number and configuration of NIC facilities: retrieval of outborn babies, transfers in and out of region, accommodation for parents, travel for parents, growth in activity, standards for staffing, the relation between high dependency care and special care, and the implications for obstetrics and Fetal Medicine.

The agreement for the region for 2004/5 is between 6899 and 9198 occupied intensive care cot days. The total cost of the consortium for 2004/5 is **£9 273 890**.

Some financial costs were shown to be minimised by centralisation on a single site but the extent of the capital building required to achieve this is as yet uncosted. However there are many other considerations to take into account when determining an optimal configuration. The appraised options ranged from a Newcastle based, single site model; a two site (Newcastle – Middlesbrough) model; two possible three site models; and the present four site model.

### *Conclusions of the review group*

In the long term, a two unit NIC configuration (Newcastle and Middlesbrough) is the favoured option. In the short term the group favours moving from the present four site model to three: James Cook (Middlesbrough), Sunderland and Newcastle.

### *New neonatal provision*

£1,277,000 capital + £637,000 new revenue is being used to open one extra intensive care space in Newcastle and one in Sunderland, bringing the regional capacity up to 30 cots with a small amount invested on Teesside to pump prime future expansion.

Some of this money will support the development of a new regional neonatal information system, compatible with that being developed for national use by the British Association of Perinatal Medicine. This should allow us to build on our existing experience with managing a networked database for the NIC units, and will generate both cross sectional activity data (for each day) and longitudinal data (for each baby). It will also allow us to benchmark against national data.

## Cross sectional activity data: referring units

Since 1992 the network has also collected cross sectional activity data from each neonatal unit that does not undertake to provide significant amounts of intensive care (non provider unit). Data for each hospital by year and for each year by hospital are available from the RMSO or from Dr DWA Milligan (D.W.A.Milligan@ncl.ac.uk). This is summarised in Table 9.2.

Table 9.2. Intensive and high dependency care days provided at "non provider" units, 2003

| | Categories of care | | | | | | |
|---|---|---|---|---|---|---|---|
| | **A** | **B** | **C** | **D** | **HD** | **LD** | **ALL** |
| Ashington | 64 | 57 | 1,718 | 487 | 121 | 2,205 | 2,326 |
| Bishop Auckland(1-9) | *27* | *58* | *1074* | *424* | *85* | *1,498* | *1,583* |
| Carlisle | 74 | 101 | 1598 | 546 | 175 | 2,144 | 2,319 |
| Darlington | 30 | 39 | 1312 | 441 | 69 | 1,753 | 1,822 |
| Durham | 38 | 116 | 1944 | 564 | 154 | 2,508 | 2,662 |
| Gateshead | 36 | 140 | 1708 | 786 | 176 | 2,494 | 2,670 |
| Hartlepool | 29 | 92 | 1631 | 592 | 121 | 2,223 | 2,344 |
| Hexham | 0 | 0 | 230 | 155 | 0 | 385 | 385 |
| N.Tyneside | 52 | 101 | 1405 | 369 | 153 | 1,774 | 1,927 |
| S.Shields | 38 | 100 | 1174 | 531 | 138 | 1,705 | 1,843 |
| Whitehaven | 42 | 42 | 1063 | 466 | 84 | 1,529 | 1,613 |
| **Non Providers 2003** | **430** | **846** | **14,857** | **5,361** | **1,276** | **20,218** | **21,494** |

*Data from Bishop Auckland relate to months 1 to 9 because of its change of status to Midwifery Led Unit during the year.
**Categories of care are graded according to the Northern Region scheme[16]. A (ventilatory support and CPAP) and B (other high dependency) are summed as 'HD', and C (low dependency 'special care') and D (normal baby care) are summed as 'LD'

For every referring hospital the numbers of high dependency days varies from year to year, so the relative numbers for each hospital in the table for 2003 can in no way be taken as indicative of any long term workload relationship between the hospitals.

[16] NORTHERN NEONATAL NETWORK. *Measuring neonatal nursing workload*. Archives of Disease in Childhood 1993;68:539-543

## Neonatal Transfers

The transfer service remains an integral part of the Provider Consortium. Activity levels have been maintained compared to 2002. Ensuring adequate nursing cover for transfers without depleting nursing numbers at the unit undertaking the transfer remains a problem and more recently ambulance related issues have been a problem for the Middlesbrough team. Table 9.3 shows the breakdown of transfers by type. Neonatal medicine transfers remain the largest group.

Table 9.3: Neonatal transfer service activity 1997-2003 by type

| | Newcastle | | | | | | | Middlesbrough | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Year** | **97** | **98** | **99** | **00** | **01** | **02** | **03** | **97** | **98** | **99** | **00** | **01** | **02** | **03** |
| **Neonatal:** | | | | | | | | | | | | | | |
| Medicine | 156 | 173 | 198 | 176 | 167 | 217 | 238 | 52 | 43 | 48 | 57 | 49 | 72 | 91 |
| Surgery | 28 | 21 | 26 | 16 | 18 | 30 | 16 | 10 | 13 | 13 | 17 | 21 | 26 | 25 |
| Cardiology | 28 | 37 | 41 | 35 | 43 | 63 | 64 | 7 | 4 | 7 | 13 | 21 | 27 | 17 |
| **Paediatric:** | | | | | | | | | | | | | | |
| Medicine | 28 | 26 | 22 | 30 | 21 | 27 | 21 | 3 | 6 | 7 | 13 | 9 | 14 | 17 |
| Surgery | 2 | 4 | 0 | 1 | 1 | 0 | 1 | 0 | 0 | 1 | 1 | 0 | 6 | 0 |
| Cardiology | 8 | 2 | 3 | 1 | 2 | 2 | 3 | 2 | 0 | 0 | 0 | 2 | 0 | 2 |
| | | | | | | | | | | | | | | |
| **ECMO** | 11 | 11 | 16 | 11 | 19 | 24 | 16 | 1 | 1 | 1 | 0 | 0 | 1 | 2 |
| **Other** | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | | | | | | | | | | | | | | |
| **Totals** | 262 | 274 | 306 | 270 | 271 | 363 | 359 | 75 | 67 | 77 | 101 | 102 | 146 | 154 |

This year (2004) we received funding from the NHS Modernisation Agency and the Changing Workforce Program to develop and run a pilot training program for paramedics and nurses to undertake neonatal transfers without junior medical staff, which, if successful, will have important implications in the long term both within the region and nationally. Six paramedics and two neonatal nurses are enrolled in the course, which is due to finish in April 2005.

## Neonatal Consortium outcome data

Not every very preterm baby born in the Region gets admitted to one of the provider NICUs, either because they die before transfer, or they remain healthy in the unit in which they were born (this mainly applies to the more mature babies of 30 weeks and upwards). The Consortium outcome data give a fair snapshot of survival to discharge which, for under 30 weeks of gestation, is probably a fair representation of overall outcomes for the region. The data are shown in table 9.4. The data by gestational age with confidence limits are summarised for the Consortium for 2003 in table 9.5.

Data have been collected across the Consortium since 1996. This allows the analysis of trends over recent years, as shown in table 9.6. The striking observation is the apparent

increase in survival over the seven year period for babies of 25 to 29 weeks of gestation, and within these gestational age ranges, especially for the 25 – 26 week babies for whom the increase is strongly statistically significant. The stability of the service configuration, referral patterns, and population geography means that these trends are most likely to be explained by improvements in perinatal care rather than being artefacts of case mix or differential referral over time.

Table 9.4: Outcome (survivors/total, to discharge) of all admissions to the Neonatal Provider Consortium by gestation and birthweight, 2003

| Gestation (weeks) | Birth weight (grams) | | | | | | | | Survivors | |
|---|---|---|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | >2499 | Totals | (%) |
| | | | | | | | | | | |
| **<24** | 0/2 | 1/5 | - | - | - | - | - | - | 1/7 | 14 |
| **24** | 1/2 | 8/16 | 4/9 | - | - | - | - | - | 13/27 | 48 |
| **25** | - | 16/19 | 10/13 | 1/1 | - | - | - | - | 27/33 | 82 |
| **26** | 1/3 | 3/3 | 26/29 | 10/11 | - | - | - | - | 40/46 | 87 |
| **27** | - | 2/4 | 9/12 | 15/17 | - | - | - | - | 26/33 | 79 |
| **28** | - | 6/7 | 8/9 | 31/33 | 9/9 | 1/1 | - | - | 55/59 | 93 |
| **29** | - | 1/1 | 3/3 | 19/19 | 25/25 | 9/12 | - | - | 57/60 | 95 |
| **30** | - | - | 3/3 | 11/11 | 23/23 | 19/19 | - | - | 56/56 | 100 |
| **31** | - | 1/1 | 4/4 | 9/9 | 19/19 | 37/37 | 5/5 | - | 75/75 | 100 |
| **32** | - | - | - | 9/9 | 11/11 | 50/51 | 28/30 | 1/1 | 99/102 | 97 |
| **33** | - | - | - | 4/4 | 7/7 | 42/43 | 36/36 | 7/7 | 96/97 | 99 |
| **34** | - | - | - | 1/1 | 6/6 | 49/49 | 75/76 | 21/22 | 152/154 | 99 |
| **35** | - | - | - | - | 3/3 | 31/31 | 36/37 | 44/45 | 114/116 | 98 |
| **36** | - | - | 1/1 | 1/1 | 3/3 | 20/20 | 25/27 | 50/51 | 100/103 | 97 |
| **37** | - | - | - | - | - | 13/14 | 23/24 | 62/64 | 98/102 | 96 |
| **38** | - | - | - | - | - | - | 12/12 | 87/90 | 99/102 | 97 |
| **39** | - | - | - | - | - | - | 10/11 | 79/82 | 89/93 | 96 |
| **40** | - | - | - | - | - | - | 5/5 | 84/90 | 89/95 | 94 |
| **41** | - | - | - | - | - | - | 1/1 | 79/79 | 80/80 | 100 |
| **>41** | - | - | - | - | - | - | 0/1 | 21/23 | 21/24 | 88 |
| **Totals** | 2/7 | 38/56 | 68/83 | 111/116 | 106/106 | 271/277 | 256/265 | 535/554 | 1387/1464 | 95 |
| **Survival (%)** | **29** | **68** | **82** | **96** | **100** | **98** | **97** | **97** | **95** | |

Table 9.5: Outcome (survivors/total, to discharge) of all admissions to the Neonatal Provider Consortium by gestation, 2003

| Gestation (w) | Survivors/Total | Survival (%) | 95% confidence limits |
|---|---|---|---|
| **<25** | 14/34 | 41.2 | 26.4 – 57.8 |
| **25-27** | 93/112 | 83.0 | 75.0 – 88.9 |
| **<28 wks** | 107/146 | 73.3 | 65.6 – 79.8 |
| **28-31** | 243/250 | 97.2 | 94.3 – 98.6 |
| **32-36** | 561/572 | 98.1 | 96.6 – 98.9 |
| **>36** | 476/496 | 96.0 | 93.9 – 97.4 |
| **All** | 1387/1464 | 94.7 | 93.5 – 95.8 |

## Neonatal Benchmarking

Benchmarking has been a nurse led activity across the Region since 1997 and has substantial credibility nationally. The benchmarking group is formed of representatives of 16 units that wish to use clinical benchmarking as a tool to improve quality care and ensure that practice is evidence based.

Clinical practice benchmarking embraces the theme of developing a new nursing role in the NHS which would reflect the changing context of care, different health needs and public perceptions[17].

The focus of the benchmarking group is to ensure quality care by comparing and sharing best practice and so working in partnership throughout the region. The framework used for benchmarking allows for individuality and shared innovations to ensure that as a group of neonatal nurses we meet the needs of the infants and their families.

The group have to date completed 15 benchmarks and the first was for neonatal transfers. The group are continually reviewing and updating benchmark tools to ensure that they keep pace with changes in practice. Benchmarking is about exploring the evidence and putting this into practice. This is an exciting initiative for neonatal nurses to work together and forge links between theory and practice.

Further details can be obtained from Yve Collingwood, Modern Matron, Newcastle Neonatal Service (Yve.Collingwood@nuth.northy.nhs.uk).

[17] DEPARTMENT OF HEALTH. *Making a Difference.* 1999.

Table 9.6: Survival by gestational age, 1996 -2003

| | | Year | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Gestation (weeks)** | | **1996** | **1997** | **1998** | **1999** | **2000** | **2001** | **2002** | **2003** |
| **<24** | **Survived/Total** | 2/2 | 0/3 | 0/2 | 2/5 | 1/8 | 1/5 | 2/6 | 1/7 |
| | **3 yr rolling mean survival (95% CI)** | | **28.6** (64.1 - 8.2) | **20.0** (51.0 - 5.7) | **20.0** (45.2 – 7.0) | **22.2** (45.2 – 9.0) | **21.1** (43.3 - 8.5) | **22.2** (45.2 – 9.0) | |
| **24** | **Survived/Total** | 10/25 | 5/16 | 3/12 | 3/18 | 4/11 | 5/15 | 22/44 | 13/27 |
| | **3 yr rolling mean survival (95% CI)** | | **34.0** (47.4 - 22.7) | **23.9** (37.9 – 13.9) | **24.4** (39.3 – 13.8) | **27.3** (41.8 – 16.3) | **44.3** (55.9 – 33.2) | **34.0** (57.0 – 36.3) | |
| **25** | **Survived/Total** | 16/24 | 13/23 | 9/22 | 8/13 | 12/20 | 12/22 | 19/24 | 27/33 |
| | **3 yr rolling mean survival (95% CI)** | | **55.1** (66.2 – 43.4) | **51.7** (64.1 – 39.2) | **52.7** (65.3 – 39.8) | **58.2** (70.3 – 45.0) | **65.2** (75.5 – 53.1) | **73.4** (81.9 – 62.8) | |
| **26** | **Survived/Total** | 16/32 | 23/34 | 8/12 | 19/32 | 12/20 | 23/26 | 24/32 | 40/46 |
| | **3 yr rolling mean survival (95% CI)** | | **60.3** (70.4 – 49.2) | **64.1** (73.9 – 53.0) | **60.9** (71.9 – 48.7) | **69.2** (78.4 – 58.3) | **75.6** (83.8 – 65.1) | **83.7** (89.5 – 75.4) | |
| **27** | **Survived/Total** | 35/44 | 36/47 | 22/24 | 24/29 | 23/27 | 33/34 | 45/50 | 26/33 |
| | **3 yr rolling mean survival (95% CI)** | | **80.9** (87.0 – 72.7) | **82.0** (88.3 – 73.3) | **86.3** (92.1 – 77.0) | **88.9** (93.9 – 80.7) | **91.0** (95.9 – 74.2) | **88.9** (93.4 – 81.9) | |
| **28** | **Survived/Total** | 43/51 | 44/51 | 32/37 | 42/58 | 41/46 | 57/63 | 42/47 | 55/59 |
| | **3 yr rolling mean survival (95% CI)** | | **85.6** (90.5 – 78.8) | **80.8** (86.4 - 73.7) | **81.6** (87.1 – 74.4) | **83.8** (88.6 – 77.5) | **89.7** (93.6 – 84.0) | **91.1** (94.5 – 85.9) | |
| **29** | **Survived/Total** | 43/51 | 51/56 | 31/35 | 47/52 | 52/56 | 63/64 | 49/52 | 57/60 |
| | **3 yr rolling mean survival (95% CI)** | | **88.0** (92.4 - 81.7) | **90.2** (94.1 – 84.2) | **90.9** (94.6 – 85.1) | **94.2** (96.8 – 89.6) | **95.3** (97.6 – 91.1) | **96.0** (98.1 – 92.0) | |

# 10. NORTHERN MULTIPLE PREGNANCY REGISTER

## Introduction

The following represents an overview of the data available for pregnancies delivering during the first five years of the register, 1998-2002; the greater benefits of this project will only become apparent with the ability to observe trends over time, and in using the register as the basis for clinically relevant prospective studies. Realising the full potential will also depend on obtaining chorionicity data which requires placentas being sent to Pathology for determination of chorionicity. Detailed analysis on the cohort is now underway.

This report relates mainly to twin pregnancies, and includes only a selection of the information collected for each pregnancy.

## Numbers, gestation, sex and chorionicity

Table 10.1. Numbers of multiple pregnancies, 1998-2002

| | 1998 | 1999 | 2000 | 2001 | 2002 |
|---|---|---|---|---|---|
| **Twin pregnancies** | 478 | 448 | 461 | 432 | 490 |
| **Twin maternities*** | 432 | 417 | 424 | 413 | 479 |
| **Triplet pregnancies** | 17 | 22 | 15 | 10 | 11 |
| **Higher order multiple pregnancies** | 2 | 1 | 1 | 2 | 0 |
| **TWINNING RATE /1000 maternities** | 13.6 | 13.6 | 14.5 | 14.4 | 16.6 |
| **Total maternities** | 31737 | 30652 | 29331 | 28718 | 28895 |

*maternities are pregnancies with at least one live birth or stillbirth

These twinning rates (13.6, 13.6, 14.5, 14.4, 16.6) compare with rates of 9.8 in 1990 and 12.0 in 1994.

In 2002, twin pregnancies were detected before 13 weeks gestation in 66.7% of registered cases, and by 18 weeks in around 92%.

Table 10.2. Gestation at diagnosis

| Gestation at diagnosis (w) | 1998 % | 1999 % | 2000 % | 2001 % | 2002 % (n) |
|---|---|---|---|---|---|
| **<9** | 22.6 | 20.8 | 26.5 | 26.2 | 22.0 (108) |
| **9-12** | 38.3 | 40.2 | 36.7 | 48.3 | 44.7 (219) |
| **13-18** | 31.6 | 24.3 | 19.5 | 20.0 | 25.7 (126) |
| **19-24** | 5.4 | 10.5 | 11.3 | 3.9 | 4.7 (23) |
| **>24** | 0.8 | 1.6 | 1.3 | 0.5 | 1.2 (6) |
| not recorded | 1.3 | 2.7 | 4.8 | 1.2 | 1.6 (8) |

Chorionicity data are currently available for 90.6% of twin maternities in 2002, an over three percent improvement since 2001. However the ideal is 100% and this figure could be approached if all twin placentas from like sex twins were sent for pathological examination. Outcome data related to chorionicity are given later in this section.

Table 10.3. Sex of infants and placental chorionicity by year

| | % maternities | | | | |
|---|---|---|---|---|---|
| | 1998 | 1999 | 2000 | 2001 | 2002 |
| **male-male** | 33.6 | 30.7 | 27.4 | 32.0 | 34.4 |
| **female-female** | 30.6 | 30.7 | 33.3 | 31.5 | 30.9 |
| **male-female** | 32.6 | 32.1 | 34.4 | 30.5 | 30.7 |
| **not known (early loss)** | 3.2 | 6.5 | 5.0 | 6.0 | 4.0 |
| | | | | | |
| **dichorionic** | 65.5 | 65.9 | 66.7 | 69.7 | 73.1 |
| **monochorionic** | 15.5 | 17.3 | 17.5 | 17.7 | 17.5 |
| **not known** | 19 | 16.8 | 15.8 | 12.6 | 9.4 |

## Outcomes

Table 10.4. Outcomes for all registered pregnancies during 2002

| TWIN 1 | TWIN 2 | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Spont. abort. | TOP | Stillbirth | ENND | LNND | PND | Survivor | Total |
| **Spont. abort.** | 8 | | | | | | | **8** |
| **TOP** | | 3 | | | | | | **3** |
| **Stillbirth** | | | 3 | | 1 | | 6 | **10** |
| **ENND** | | | 1 | 6 | | | 3 | **10** |
| **LNND** | 1 | | | | | | 3 | **4** |
| **PND** | | | | | | | 3 | **3** |
| **Survivor** | 16 | | 8 | 3 | 1 | 1 | 423 | **452** |
| **Total** | **25** | **3** | **12** | **9** | **2** | **1** | **438** | **490** |

Spont. abort. = spontaneous abortions, including 'vanishing' twins
TOP = termination of pregnancy
ENND / LNND / PND = early / late neonatal death /postneonatal death

### *Mortality*

- 33 fetuses were lost spontaneously before 24 weeks in 2002.
- Among the 479 maternities in 2002 there were 22 stillbirths (20 antepartum and 2 intrapartum), 19 early neonatal deaths, six late neonatal and four postneonatal deaths.

- In 2002 the overall perinatal mortality rate was 42.8/1000 total twin births (24.2 in 2001), and the infant mortality rate 31.6 /1000 livebirths (20.1 in 2001) (Northern Region 2002 singleton perinatal mortality rate = 7.1 per 1000 total singleton births; singleton infant mortality rate = 3.5 per 1000 livebirths).
- Perinatal mortality was slightly higher for twin 2 (44.1/1000) than twin 1 (42.0/1000).
- Chorionicity data are currently available for 434 maternities, and for 37 of the 40 maternities where there was at least one stillbirth or infant death. The monochorionic group (n=84) includes 12 stillbirths and 6 early neonatal deaths, giving a perinatal mortality rate of 107.1 /1000 total births. Within the dichorionic group (n=350) there were 10 stillbirths and 9 early neonatal deaths, giving a perinatal mortality rate of 27.1/1000 total births. However, given that chorionicity data is incomplete these rates must be treated with caution.

A summary of mortality data for 1998-2002 is given in table 10.5. Small numbers of outcomes means that there is considerable year by year variation.

Table 10.5. Mortality data for 1998-2002

| | 1998 | 1999 | 2000 | 2001 | 2002 |
|---|---|---|---|---|---|
| **Losses <24w (all pregnancies)** | 7.5% | 7.2% | 6.8% | 5.4% | 4.0% |
| | | | | | |
| **Stillbirths (n)** | 15 | 19 | 17 | 6 | 22 |
| **Early NND (n)** | 10 | 25 | 18 | 14 | 19 |
| **Late NND (n)** | 5 | 8 | 3 | 2 | 6 |
| | | | | | |
| **PNMR ( /1000 total births)** | 28.9 | 52.8 | 41.3 | 24.2 | 42.8 |
| **Infant mortality ( /1000 livebirths)** | 18.0 | 48.2 | 29.5 | 20.1 | 31.6 |
| | | | | | |
| **PNMR – monochorionic** | 67.2 | 69.4 | 69.6 | 27.4 | 107.1 |
| **PNMR – dichorionic** | 24.7 | 43.6 | 28.3 | 26.0 | 27.1 |

NND = neonatal deaths
PNMR = perinatal mortality rate

### *Pregnancies with one intrauterine death and one livebirth*

In 17 pregnancies one twin was liveborn after intrauterine death (IUD) of the other twin before 24 weeks gestation; chorionicity is available for only eight of these cases, which is not surprising given the difficulty of establishing chorionicity by pathological examination many weeks after early death of one twin. In a further 14 pregnancies, one twin was stillborn and the other was a liveborn twin who survived the first year of life; chorionicity is currently available for all of these (dichorionic in 9, monochorionic in 5). In total, therefore there were 31 twin maternities (6.5%) with one first-year survivor; in those cases where placentation was monochorionic there is the potential for neurological impairment in the survivor due to haemodynamic events following death of the other twin.

### *Congenital anomalies*

In 2002, 36 pregnancies were complicated by anomaly, involving 37 infants (3.8% of 980 infants from 490 pregnancies).

- **Chorionicity** was known for 35 pregnancies: 27 dichorionic, 8 monochorionic.

- **Outcomes**: of the 36 pregnancies, one resulted in a termination; of 30 liveborn twins with congenital anomalies, 25 (83%) were alive at one year.

- **Overall for 1998-2002:** 155 pregnancies were complicated by anomaly, involving 176 individuals (3.8% of all twins), with the following outcomes: 12 terminated pregnancies; two selective reductions; 128 liveborn twins with 107 (84%) alive at one year. Types of anomaly for 1998-2002 are described in table 10.6.

Table 10.6. Types of anomaly 1998-2002

| Type of anomaly | Number of twins |
|---|---|
| **Anomalies associated with twinning** | |
| conjoined twins | 8 (4 sets) |
| TRAP sequence (acardiac twins) | 3 |
| **Chromosomal anomalies** | |
| trisomy 21 | 8 |
| trisomy 18 | 5 |
| other | 10 |
| **Central nervous system** | |
| neural tube defects | 13 |
| other | 9 |
| **Cardiovascular** | |
| isolated VSD | 25 |
| other | 21 |
| **Abdominal wall defects** | 5 |
| **Renal/urinary tract** | |
| Renal dysplasia | 4 |
| hydronephrosis | 8 |
| other | 5 |
| **Other anomalies** | 52 |
| **Total** | 176 |

## Management of labour and delivery

The following data can be compared with that given for all births in Chapter 7 – Maternity Care.

- The onset of labour was spontaneous in 225 maternities (46.9%) and induced in 108 (22.7%). There was no labour in 135 (28.2%). The corresponding figures for 2001 were 46.9%, 20.6%, and 32.0%, respectively.
- The mode of delivery for both twins (479 maternities) is summarised in table 10.7. The proportion of infants delivered by caesarean section in 2002 was slightly higher than that in 2001.

Table 10.7 Mode of delivery by year

| Mode of delivery | 1998 | | 1999 | | 2000 | | 2001 | | 2002 | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Twin 1 (%) | Twin 2 (%) | Twin 1 (%) | Twin 2 (%) | Twin 1 (%) | Twin 2 (%) | Twin 1 (%) | Twin 2 (%) | Twin 1 (%) | Twin 2 (%) |
| **Normal** | 41.9 | 25 | 36 | 19 | 33.5 | 21.7 | 36.8 | 21.8 | 35.9 | 22.5 |
| **Forceps** | 4.9 | 4.1 | 6 | 4.5 | 5.0 | 2.1 | 5.1 | 3.3 | 5.0 | 2.9 |
| **Ventouse** | 7.7 | 5.1 | 5.5 | 4.8 | 4.5 | 4.0 | 6.3 | 4.4 | 5.6 | 4.2 |
| **Breech** | 1.9 | 18 | 2.6 | 13 | 1.7 | 13.4 | 2.2 | 14.3 | 1.3 | 10.6 |
| **Section** | 43.5 | 44 | 49 | 52 | 51.6 | 51.4 | 49.1 | 49.6 | 50.5 | 51.8 |
| **Other** | - | - | - | - | 0.2 | 0.2 | 0.2 | 0.2 | - | - |
| **Unrecorded** | 0.7 | 4.4 | 1 | 7 | 3.5 | 7.1 | 0.2 | 6.3 | 1.7 | 7.9 |
| **TOTAL** | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |

## Gestation at delivery

Nearly 38% of the 479 maternities in 2002 were delivered before 37 weeks, the percentage of preterm deliveries in 2002 was much lower that in previous years (table 10.8).

Table 10.8 Gestation at delivery

| gestation (wks) | 1998 | | 1999 | | 2000 | | 2001 | | 2002 | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** | **n** | **%** |
| **≤23** | 1 | 0.2 | 6 | 1.4 | 4 | 0.9 | 5 | 1.2 | 2 | 0.4 |
| **24-27** | 10 | 2.3 | 14 | 3.4 | 11 | 2.6 | 8 | 1.9 | 13 | 2.7 |
| **28-31** | 24 | 5.6 | 39 | 9.4 | 32 | 7.5 | 33 | 8.0 | 36 | 7.5 |
| **32-36** | 176 | 40.7 | 168 | 40.3 | 171 | 40.3 | 168 | 40.7 | 130 | 27.1 |
| **37-41** | 219 | 50.7 | 188 | 45.1 | 192 | 45.3 | 195 | 47.2 | 297 | 62.0 |
| **>41** | 2 | 0.5 | 2 | 0.5 | 6 | 1.4 | 2 | 0.5 | 1 | 0.2 |
| **unknown** | | | | | 8 | 1.9 | 2 | 0.5 | | |

## Admission to SCBU

In 2002, 37.1% of the 469 liveborn first twins were admitted to SCBU, compared with 40.4% of 450 liveborn second twins. The corresponding figures for 2001 were 42.3% and 45.3%.

## Publications based on the MPR data

- S.V. GLINIANAIA, C. WRIGHT, J. RANKIN, S. STURGISS, M. WARD-PLATT, U. WARIYAR, M. RENWICK. *Fetal losses and infant deaths in twins: a retrospective cohort study in the North of England*. Arch Dis Child 2004; 89 (Suppl. 1): A8. - Presented at the 8th Spring Meeting of the Royal College of Paediatrics and Child Health, 29 March-1 April 2004, York.
- GLINIANAIA SV, RANKIN J, WRIGHT C, STURGISS S, RENWICK M. *A Multiple Pregnancy Register in the North of England.* Twin Research 2002; 5 (5): 436-439.

### *Students projects in 2004 involving MPR data*

- K. SMALLSHAW. Epidemiology of twin pregnancy in the North East – an audit of data from 1998 to 2002
- V. HEMMING. MRes dissertation: Umbilical artery Doppler ultrasound abnormalities and birth outcomes in twins.

# 11. NORTHERN CONGENITAL ABNORMALITY SURVEY (NORCAS)

## Background

The Northern Congenital Abnormality Survey (NorCAS, formerly the Fetal Abnormality Survey) was established in 1985 following a pilot year. Its remit is to obtain data on all congenital abnormalities arising within the population of the former Northern Region whether resulting in miscarriages, terminations of pregnancy or registered births and whether diagnosed antenatally or later. Since the reorganization of the NHS boundaries in 1995, data from South Cumbria is no longer registered onto the Survey. Mothers resident in the Region who deliver outside the region are included but the Survey excludes cases from mothers resident outside the region who deliver within the region.

NorCAS aims to provide continuous epidemiological monitoring of the frequency and nature of congenital anomalies for the population of the former Northern Region, and to support research into the causes and consequences of these conditions. More specifically, the objectives of NorCAS are to inform:

- Surveillance and analysis of congenital anomaly prevalence;
- Local and regional audit in support of clinical governance processes in NHS Trusts across the region;
- Provision of accurate and timely information on prevalence rates and expected outcomes of affected pregnancies/ infants;
- Epidemiological and clinical research approved by research ethics committees.

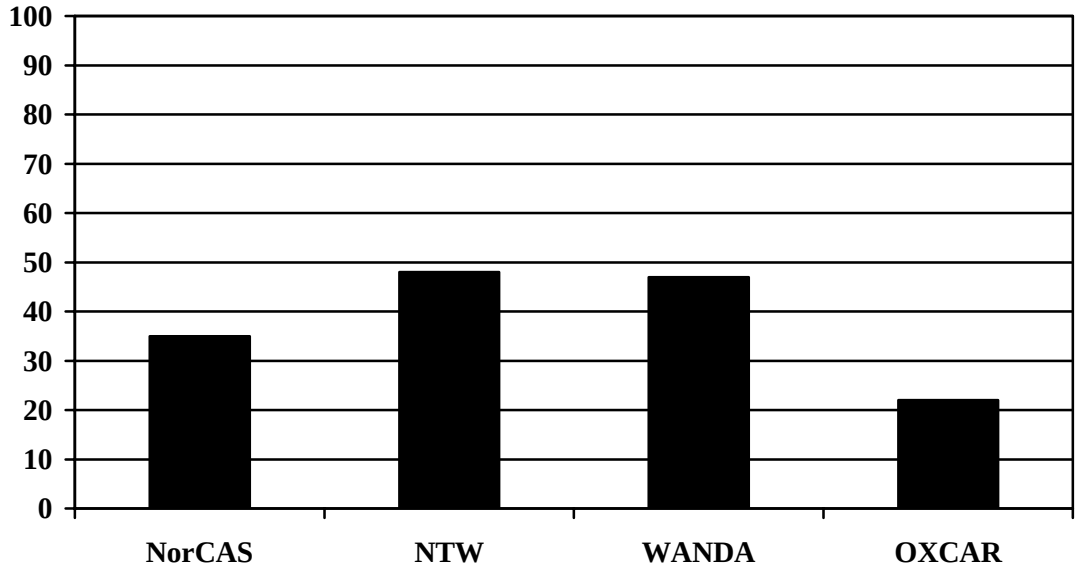
## Register Developments

### *Data sharing*

Data notification from NorCAS to the National Congenital Anomaly System (NCAS), operated by the Office for National Statistics, began in January 2003. NCAS is known to be incomplete and a recent paper involving data from four English congenital anomaly registers has attempted to assess the completeness of reporting for the study period 1991-99[18]. Figure 11.1 shows the variation in ascertainment in NCAS across local register areas (excluding terminations of pregnancy from local registers as these are not collected by NCAS). The highest ascertainment to NCAS was from the regions covered by the North Thames West (NTW) and Wessex Antenatally Diagnosed Congenital Anomalies Register (WANDA) and the lowest from the Oxford Congenital Malformation Register (OXCAR). Table 11.1 shows that overall ascertainment by the NCAS was 40% (34% for chromosomal anomalies and 42% for non-chromosomal anomalies) and varied markedly by anomaly. Data transfer between regional registers and NCAS will go a long way to improve NCAS ascertainment as well as the continued validation of regional data.

[18] BOYD P, ARMSTRONG B, DOLK H, BOTTING B, PATTENDEN S, ABRAMSKY L, RANKIN J, VRIJHEID M, WELLESLEY D. *Birth defect surveillance in England – ascertainment deficiencies in the national system.* BMJ 2004; in press

Figure 11.1: Percentage of all congenital anomalies in the NCAS compared to local registers, by register




NorCAS is now a full member of the European Surveillance of Congenital Anomalies (EUROCAT), a network of European congenital anomaly registers from 31 countries[19]. The first download of data will be transferred to EUROCAT in early 2005. NorCAS continues to be an active member of the British Isles Network of Congenital Anomaly Registers (BINOCAR)[20].

### *NorCAS case validation*

Validation of a register is one of the most important issues in maintaining a high quality and accurate register[21]. Through annual cross validations with the Paediatric Cardiology Database at the Freeman Hospital and the Cytogenetics database, we are confident that case ascertainment is high for these anomaly subtypes. For other anomaly groups, the situation is less clear. In the continual strive for complete case ascertainment, we undertook a validation exercise using congenital intestinal anomalies as the example. Two sources of data were compared for 1991-2001, the RVI surgical list and NorCAS. As shown in table 11.2, NorCAS recorded 81.7% of all congenital intestinal anomalies; 87.5% of cases with small intestinal atresia (SIA); 89.4% of cases with large intestinal atresia (LIA); and 70.9% of other gastrointestinal anomalies. 12.5% of SIA cases and 10.6% of LIA cases were only found in the RVI database. The underreporting of cases, especially of other GI anomalies, may have resulted from the diagnosis not being made in the first year of life and staff not being aware that congenital anomalies should be notified to NorCAS up to age 16 years. NorCAS records cases of congenital intestinal atresia not occurring in livebirths, highlighting the value of local congenital anomaly registers.

[19] EUROCAT. Report 8. *Surveillance of congenital anomalies in Europe 1980-99*. University of Ulster, 2002.

[20] BINOCAR. Online website. http://www.binocar.org

[21] NEWTON, J. AND S. GARNER. (2002). *Disease Registers in England*. Institute of Health Sciences, Oxford.

Table 11.1: Number of cases of congenital anomalies ascertained by NCAS and by the four local registers (excluding termination of pregnancy from local register data)

| Anomaly Group and sub groups | No. of cases in NCAS | No. of cases among local registries | NCAS cases as % of local registry cases |
|---|---|---|---|
| **All cases** | 2483 | 6240 | 40% |
| | | | |
| All Chromosome anomalies** | 555 | 1641 | 34% |
| Down's Syndrome | 428 | 834 | 51% |
| All non chromosome anomalies* | 1928 | 4599 | 42% |
| **Some specific non-chromosomal anomalies** | | | |
| All Neural Tube defects | 119 | 176 | 68% |
| Spina bifida | 84 | 112 | 75% |
| Cardiac anomalies (excluding VSDs) | 241 | 1800 | 13% |
| Hypoplastic Left Heart | 19 | 98 | 19% |
| Fallots Tetralogy | 26 | 140 | 19% |
| Cleft Lip | 452 | 547 | 83% |
| Cleft Palate | 208 | 292 | 71% |
| Digestive system (fistulae and atresias) | 188 | 415 | 45% |
| Gastroschisis*** | 58 | 132 | 44% |
| Exomphalos*** | 28 | 58 | 48% |
| Diaphragmatic Hernia*** | 29 | 85 | 34% |
| Cystic kidneys | 82 | 299 | 27% |
| Limb reduction | 217 | 246 | 88% |

* This includes anomalies coded with the following ICD10 codes:
Q00-03, Q041-042, Q05, Q110-112, Q160, Q172, Q20, Q211-219, Q22-23, Q25-26, Q300-348, Q36-37, Q35, Q390-394, Q41, Q42, Q600-605, Q61, Q641-643, Q645, Q71-73, Q77, Q78, Q790-793,
** Q90-94, Q96-99
*** Analysis limited to 1995-1999 to achieve coding comparability between NCAS and local register data.

### *Links with the Human Fertilisation & Embryology Authority (HFEA)*

The RMSO has been working with the HFEA to improve outcome reporting of anomalies to HFEA, in particular providing advice on data collection, validation and anomaly coding.

### *Routine Surveillance*

Work is underway to improve active surveillance of congenital anomalies in the North East by adopting an appropriate surveillance system. Two different systems will be explored – the existing EUROCAT Data Management Programme and the use of control charts. Recommendations will be made to the NorCAS Steering Group in autumn 2005.

Table 11.2: Source of data on all cases of congenital intestinal anomalies

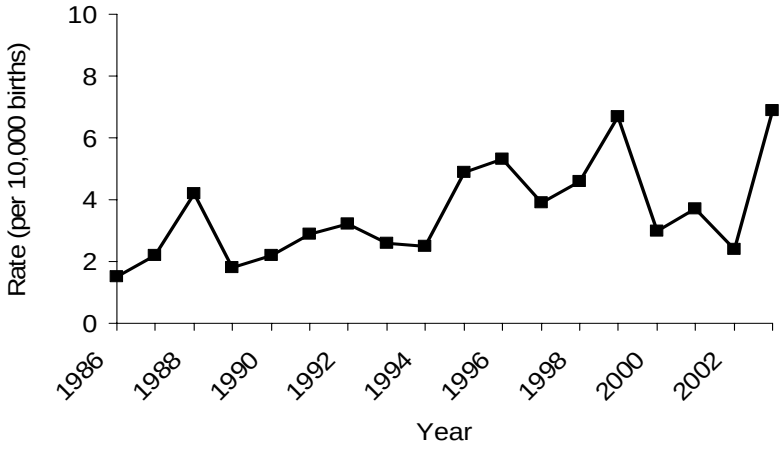
| TYPE | | SOURCE | | | | Total |
|---|---|---|---|---|---|---|
| | | NorCAS only [a] | NorCAS only (live births) [b] | RVI only | Both NorCAS & RVI | |
| Small intestinal atresia | No. (%) | 11 (10.6) | 3 (2.9) | 13 (12.5) | 77 (74.0) | 104 |
| Large intestinal atresia | No. (%) | 31 (22.0) | 7 (5.0) | 15 (10.6) | 88 (62.4) | 141 |
| Other gastrointestinal anomalies | No. (%) | 11 (6.7) | 3 (1.8) | 48 (29.1) | 103 (62.4) | 165 |
| Total | No. (%) | 53 (12.9) | 13 (3.2) | 76 (18.5) | 268 (65.4) | 410 |

[a] Outcomes are miscarriage, termination of pregnancy, antepartum and intrapartum stillbirths.
[b] Outcomes are early and late neonatal death, postnatal death, and alive at 1 year

### *Gastroschisis*

An increase in the prevalence of gastroschisis has been observed regionally, nationally and internationally. Figure 11.2 shows the year on year fluctuation in prevalence of gastroschisis in the Northern Region. Although there was a reduction in the prevalence rate in 2000 and 2001, the rate has increased again in 2003 to 6.9 per 10,000 births. The continual rise is attracting much attention nationally and is the subject of several ongoing investigations.

Fig 11.2: Secular change in total prevalence of gastroschisis in the Northern Region, 1986-2003.



### *Down's Syndrome Screening Programme Audit*

From January 2004, the Regional Maternity Survey Office is responsible for collecting the data for the auditing of the National Down's Syndrome Screening Programme for the North East Region. NorCAS is working closely with the Northern Genetics Service and Regional Antenatal Screening co-ordinator to set up an efficient system of data collection and sharing. This project entails collecting details of antenatal screening of all trisomies 13, 18 and 21 that goes beyond our standard NorCAS form and will require collecting further data from all units.

### *Future developments*

The introduction of first trimester antenatal ultrasound scanning, three dimensional obstetric ultrasound and more extensive neonatal screening programmes are likely to increase the ascertainment of congenital anomalies and will have unknown effects on rates of termination of pregnancy. NorCAS is well placed to undertake the necessary external monitoring and audit of these developments as part of its routine function.

## Ongoing research

The following research projects are ongoing:

- Small intestinal atresia, 1991-2001; occurrence and antenatal diagnosis.
- Congenital anomalies and air pollution; the CAAP study.
- Recreational drug use: a risk factor for gastroschisis?
- A feasibility study of the construction of a register of cryptorchidism and hypospadias for the North of England.
- Is congenital abnormality a risk factor for childhood cancer?

## Publications using NorCAS data in the last two years

- RANKIN J, WRIGHT C. *Survival analysis of congenital anomaly sub types is needed.* Archives of Disease in Childhood. 2003 (electronic response).

- DOLK H, VRIJHEID M, SCOTT JES, ADDOR M-C, BOTTING B, DE VIGAN C, et al. *Towards the effective surveillance of hypospadias.* Environmental Health Perspectives. 2004; 112: 398- 402.

- CLAUDE MC, CALZOLARI E, DE VIGAN C, DE WALLE H, DOLK H, GARNE E, et al . *An assessment and analysis of surveillance data on hypospadias in Europe, 2003*. Eurocat Special Report, Eurocat Central Registry, 2004.

- CRESSWELL PA, SCOTT JES, PATTENDEN S, VRIJHEID M. *Risk of congenital anomalies near the Byker waste combustion plant.* Journal of Public Health Medicine. 2003;25:237-42.

- WREN C, BIRRELL G, HAWTHORNE G. *Cardiovascular malformations in infants of diabetic mothers.* Heart. 2003;89:1217-20.

- LOWRY R, STEEN N, RANKIN J. *Water fluoridation, stillbirths and congenital abnormalities.* Journal of Epidemiology & Community Health. 2003;57:499-500.

- BELL R, RANKIN J, DONALDSON LJ. *Down's syndrome: occurrence and outcome in the north of England, 1985-99*. Paediatric & Perinatal Epidemiology. 2003;17:33-39.

# 12. NORTH OF ENGLAND COLLABORATIVE CEREBRAL PALSY SURVEY (NECCPS)

## Background

Cerebral palsy is the commonest cause of long-term physical disability in children. The NECCPS began in 1994 as a prospective cerebral palsy survey across all districts in the former Northern Regional Health Authority. Before this time, a smaller survey had operated in the Tyneside area from 1960 births.

NECCPS is collaboration between paediatricians across the region (each district has a convenor) who use the survey for service planning, audit and research. For some years, NECCPS has been housed at the RMSO and for the last two years has been formally under the umbrella of the RMSO.

The survey holds data on 780 children born between 1960 and 1990 in the Northumberland, Newcastle and North Tyneside districts. As of September 2004, data on a further 987 children from the former Northern Region are held for 1991 births onwards. There is a wealth of information on each child including type of cerebral palsy, birth weight, gestation, current and birth postcodes. Uniquely, data are also held from the Lifestyle Assessment Questionnaire – an instrument specifically designed for children with cerebral palsy to measure the impact of disability on the child and family.

More information is available in successive annual reports available from the RMSO office; the most recent report was specifically aimed at parents of children with cerebral palsy.

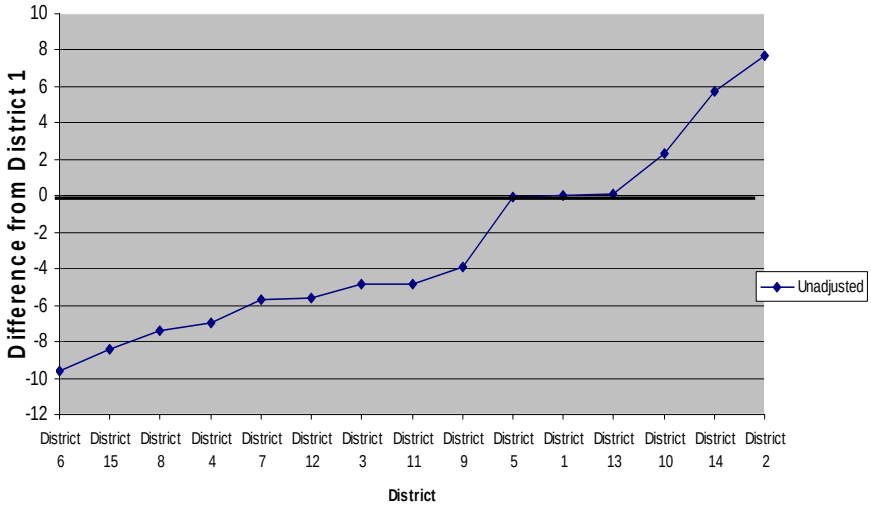
## Participation

NECCPS has close links with other UK and European cerebral palsy registers. Research publications have covered trends in prevalence by birth weight and gestation, life expectancy, development of the Lifestyle Assessment Questionnaire, qualitative work with families on what they want from a cerebral palsy register, and analysis of how participation (formerly called handicap) varies with district even after severity of impairment has been controlled for.

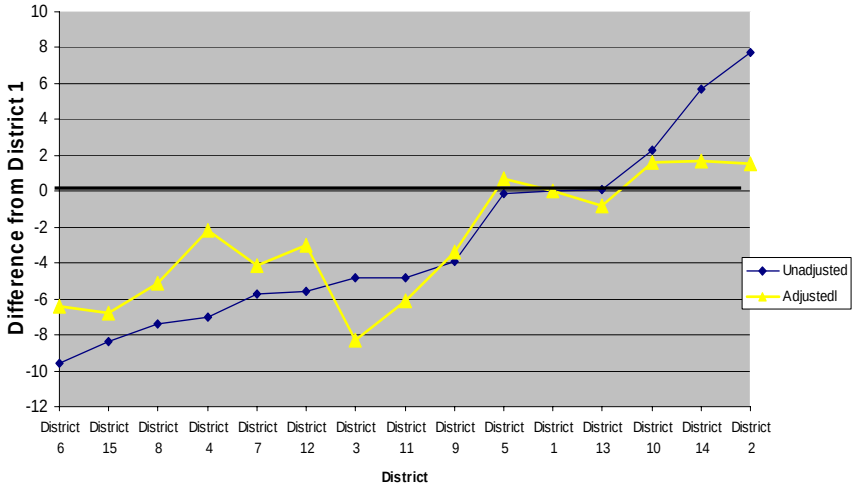
Below are two graphs from a recent publication. The first shows that the participation of 5 year old children in the North of England varies with the district in which they live.

The second graph shows that variation remains when the graph is adjusted to control for severity of cerebral palsy and social factors. The implication is that the environment is very important in determining participation. Newcastle now co-ordinates a European study which examines how participation varies in nine European centres and which features of the environment best promote participation.

## Mean LAS (participation restriction)




## Mean LAS (participation restriction) when severity and social factors are controlled for




### Working with Parents

When the survey was started, links with parents were not well established. We are remedying this in the following ways:

- The survey has conducted a piece of qualitative work with 12 families to find out what kind of information parents want and need about such a survey (see publications, Colligan et al).

- An information sheet is available about the survey.
- Permission from parents is now sought before their child's name is submitted to the survey. In the past, this permission was not sought until their child reached age 4 years.
- The annual report in 2002 was designed specifically for parents and the general public.
- The programme of the annual meeting contains some talks specifically for parents.
- Thirty parents attended the last annual meeting; they decided they wanted to explore the possibility of a parents' group and the survey staff are facilitating this.

## Current data

Tables 12.1 and 12.2 show the most recent data on rates of cerebral palsy in children born to resident mothers.

Table 12.1: Registrations (numbers) by former health "districts".

| Collaborating Area | Registrations of CP by year of birth | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | Not complete | | | |
| | 91 | 92 | 93 | 94 | 95 | 96 | 97 | 98 | 99 | 00 |
| Northumberland | 9 | 13 | 4 | 7 | 7 | 11 | 4 | 4 | 5 | 3 |
| Newcastle | 10 | 9 | 13 | 5 | 6 | 9 | 9 | 6 | 2 | 5 |
| North Tyneside | 10 | 10 | 2 | 2 | 3 | 4 | 3 | 6 | 6 | 1 |
| **Newcastle & North Tyneside** | **20** | **19** | **15** | **7** | **9** | **13** | **11** | **12** | **8** | **6** |
| Gateshead | 9 | 8 | 5 | 5 | 2 | 6 | 8 | 2 | 6 | 6 |
| South Tyneside | 4 | 4 | 9 | 7 | 6 | 3 | 6 | 4 | 3 | 2 |
| **Gateshead & South Tyneside** | **13** | **12** | **14** | **12** | **8** | **9** | **14** | **6** | **9** | **8** |
| Sunderland | 4 | 13 | 8 | 17 | 11 | 8 | 10 | 5 | 6 | 5 |
| North Tees | 7 | 6 | 8 | 8 | 19 | 7 | 15 | 11 | 6 | 2 |
| South Tees | 14 | 13 | 14 | 8 | 15 | 14 | 8 | 8 | 7 | 5 |
| Hartlepool | 2 | 2 | 6 | 9 | 3 | 2 | 6 | 8 | 3 | 2 |
| **Tees** | **23** | **21** | **28** | **25** | **27** | **23** | **29** | **27** | **16** | **9** |
| N.W. Durham | 4 | 0 | 2 | 0 | 3 | 6 | 4 | 2 | 4 | 3 |
| Durham | 4 | 4 | 6 | 4 | 2 | 2 | 5 | 3 | 1 | 0 |
| S.W. Durham | 8 | 12 | 6 | 4 | 5 | 7 | 6 | 5 | 3 | 2 |
| Darlington | 3 | 3 | 7 | 4 | 1 | 5 | 5 | 1 | 2 | 2 |
| **Co. Durham** | **19** | **19** | **21** | **12** | **11** | **20** | **20** | **1** | **10** | **7** |
| W. Cumbria | 4 | 2 | 2 | 2 | 3 | 5 | 6 | 8 | 1 | 3 |
| E. Cumbria | 6 | 1 | 4 | 7 | 3 | 7 | 5 | 2 | 4 | 3 |
| **North Cumbria** | **10** | **3** | **6** | **9** | **6** | **12** | **11** | **10** | **5** | **6** |
| **North of England Excluding S. Cumbria** | **98** | **100** | **96** | **89** | **79** | **96** | **100** | **75** | **59** | **44** |

Table 12.2: Registration rates by former health "districts".

| Collaborating Area | Three year rolling registration rate per 1,000 live births | | | | | |
|---|---|---|---|---|---|---|
| | 1991-93 | 1992-94 | 1993-95 | 1994-96 | 1995-97 | 1996-98 |
| Northumberland | 2.43 | 2.28 | 1.75 | 2.50 | 2.26 | 1.97 |
| Newcastle | 2.96 | 2.57 | 2.33 | 1.99 | 2.45 | 2.53 |
| North Tyneside | 3.05 | 2.03 | 1.04 | 1.37 | 1.53 | 2.01 |
| **Newcastle & North Tyneside** | **3.00** | **2.35** | **1.82** | **1.675** | **2.08** | **2.32** |
| Gateshead | 2.88 | 2.44 | 1.66 | 1.84 | 2.29 | 2.35 |
| South Tyneside | 2.81 | 3.43 | 3.88 | 2.92 | 2.79 | 2.52 |
| **Gateshead & South Tyneside** | **2.85** | **2.88** | **2.64** | **2.31** | **2.51** | **2.42** |
| Sunderland | 2.08 | 3.33 | 3.31 | 3.41 | 2.83 | 2.31 |
| North Tees | 2.80 | 3.08 | 3.65 | 3.63 | 4.79 | 5.12 |
| South Tees | 3.30 | 2.89 | 3.17 | 3.28 | 3.40 | 2.84 |
| Hartlepool | 2.57 | 4.49 | 4.77 | 3.86 | 3.16 | 4.88 |
| **Tees** | **3.02** | **3.21** | **3.59** | **3.48** | **3.79** | **3.90** |
| N.W. Durham | 1.85 | 0.64 | 1.64 | 3.09 | 4.49 | 4.22 |
| Durham | 1.54 | 1.60 | 1.44 | 0.98 | 1.11 | 1.25 |
| S.W. Durham | 4.36 | 3.84 | 2.75 | 3.00 | 3.65 | 3.70 |
| Darlington | 2.68 | 2.98 | 2.61 | 2.21 | 2.34 | 2.36 |
| **Co. Durham** | **2.55** | **2.33** | **2.06** | **2.06** | **2.47** | **2.50** |
| W. Cumbria | 1.52 | 1.25 | 1.64 | 2.25 | 2.85 | 3.51 |
| E. Cumbria | 1.68 | 1.84 | 2.14 | 2.75 | 2.71 | 2.84 |
| **North Cumbria** | **1.61** | **1.59** | **1.94** | **2.54** | **2.78** | **3.19** |
| **North of England (excludes South Cumbria)** | **2.60** | **2.61** | **2.50** | **2.57** | **2.73** | **2.75** |

## Publications using NECCPS data in the last two years


- JESSEN EC, COLVER AF, MACKIE PC, JARVIS SN. *Development and validation of a tool to measure the impact of childhood disabilities on the lives of children and their families*. Child: care, health and development. 2003:29:21-34.
- COLVER AF, SETHU T. *The term diplegia should be abandoned*. Archives of Disease in Childhood. 2003:88:286-290.
- *NECCPS Annual Report 2002*. Designed for parents and lay readers. Available from the RMSO.
- COLVER AF. *The benefits of a population register of cerebral palsy*. Indian Paediatrics. 2003:40:639-644.
- JARVIS S, GLINIANAIA S, TORRIOLI M, PLATT M, MICELI M, JOUK P, JOHNSON A, HUTTON J, HEMMING K, HAGBERG G, DOLK H, CHALMERS J, on behalf of the Surveillance of Cerebral Palsy in Europe (SCPE) collaboration of European Cerebral Palsy Registers. *Cerebral palsy and intrauterine growth in single births: European collaborative study.* Lancet. 2003: 362:1106-1112.

- COLLIGAN J. MILLER J, COLVER AF. *A qualitative study, using focused interviews, of the information needs of families whose children's names are on a cerebral palsy register*. Child: Care, health and development. 2003:29:465-471.
- HAMMAL D, JARVIS SN, COLVER AF. *Participation of children with cerebral palsy is influenced by where they live.* Developmental Medicine and Child Neurology. 2004:46:292-298.
- MIHAYLOV SI, JARVIS SN, COLVER AF, BERESFORD B. *Identification and description of environmental factors that influence participation of children with cerebral palsy.* Developmental Medicine and Child Neurology. 2004:46: 299-304.
- TOPP M et al. *Multiple birth and cerebral palsy in Europe: a multi-centre study*. Acta Obstetrica Scandinavia. In press 2004.
- CANS C et al. *Cerebral palsy of post-neonatal origin: characteristics and risk factors*. Pediatric and Perinatal Epidemiology. 2004:18:214-220.

# 13. REPORT FROM RMSO ADVISORY GROUP

This group was formed in March 2003 with the following terms of reference:

1. Members of the group commit to meeting on a quarterly basis. Additional members to be appointed at the group's discretion.
2. The Chair will be a non clinical member of the group and elected by the group.
3. To explore, in relation to the linked surveys, the:
    - Ethical framework
    - Legal framework
    - Provision of information to those who may be registered, the wider public and professionals
    - Development of public involvement
    - Approach to seeking consent
4. To develop an explicit ethical framework for the surveys in the light of existing national guidance and future societal change.
5. To establish principles for public information and involvement and the seeking of consent.
6. To define the tasks in relation to 5 above.
7. To monitor progress against the completion of these tasks.
8. To challenge the Director, Clinical Director and Research Director to work within the emerging frameworks.

The Group was formed as a result of growing concern among researchers that they were under pressure to seek consent to retain data where the very process of seeking that consent could cause distress. Information technology has enormously increased the quantity of data which can be stored: this has raised concern for members of the public who may feel that they no longer control the information retained about them. Researchers fear that data that may be useful in the future could be lost irrevocably. At a personal level they can see the fruits of years of hard work under threat.

The Advisory group has now met six times. The following actions have been encouraged and supported by the Group.

- The Group has agreed the content of a public information leaflet after consultation through members.
- RMSO information is now available at www.nepho.org.uk, including a summary report.
- The RMSO Annual Report 2002 is now available at www.nepho.org.uk.

- A specific linked website www.nrmso.org.uk is being developed within the NEPHO website.
- A "Citizen's Jury" approach to confidentiality issues is being explored through the Chair.

**Bryan Vernon**
**Chair**
**December 2004**

# APPENDIX (I) RMSO STAFF AND CONTACT DETAILS

## RMSO Staff and contact details

| | | |
|---|---|---|
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| Dr Martin Ward-Platt | Clinical Director | m.p.ward-platt@ncl.ac.uk |
| Marjorie Renwick | CEMACH Regional Manager/ RMSO Operational Manager | marjorie.renwick@rmso.org.uk |
| Mary Bythell | Data Manager: NorCAS/ Cerebral Palsy | Mary.Bythell@newcastle.ac.uk |
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# APPENDIX (II) RMSO ADVISORY GROUP MEMBERSHIP

## (current)

| | |
|---|---|
| Dr Joan Arvold | Programme Director |
| Dr Allan Colver | Consultant Paediatrician |
| Dr Tricia Cresswell | Director RMSO/Director of Public Health |
| Dr Elizabeth Dillon | Consultant Radiologist |
| Prof. Erica Haimes* | Director of PEALS Unit, University of Newcastle |
| Dr Sally Lynch* | Consultant Clinical Geneticist |
| Ms Kath Mannion | LSA Midwifery Officer |
| Mrs Joan Oliver | Neonatal Nurse Practitioner |
| Prof Louise Parker | Paediatric Epidemiologist |
| Dr Judith Rankin | Principal Research Associate |
| Dr Sam Richmond | Consultant Paediatrician |
| Mrs Marjorie Renwick | Regional CEMACH Manager |
| Dr Anne Ryall* | Consultant Obstetrician |
| Rev Bryan Vernon | Lecturer in Health Care Ethics/**Chair** |
| Dr Martin Ward-Platt | Clinical Director RMSO/Consultant Paediatrician |
| Dr Chris Wright | Consultant Perinatal Pathologist |

* left group during 2004

# APPENDIX (III) MEMBERSHIP OF STEERING GROUPS

## Perinatal Mortality Survey (PMS/CEMACH) (current)

| | |
|---|---|
| Dr Allan Colver | Consultant Paediatrician |
| Dr Tricia Cresswell | Director RMSO/Director of Public Health |
| Mr David Evans | Consultant Obstetrician |
| Dr Alan Fenton | Consultant Neonatologist |
| Dr Bill Lamb* | Consultant Paediatrician |
| Ms Kath Mannion | LSA Midwifery Officer |
| Mr Paul Moran | Consultant in Fetal Medicine |
| Dr Peter Quigley | General Practitioner |
| Mr Willie Reid | Consultant Obstetrician/ **Chair** |
| Mrs Marjorie Renwick | Regional CEMACH Manager |
| Dr Anne Ryall* | Consultant Obstetrician |
| Dr Chris Wright | Consultant Perinatal Pathologist |
| Dr Jonathan Wyllie | Consultant Neonatologist |

*Left group during 2004

## Northern Congenital Abnormality Survey (NorCAS) (current)

| | |
|---|---|
| Mr John Atkins | Retired Consultant Obstetrician |
| Prof John Burn | Clinical Geneticist |
| Mrs Mary Bythell | Data Manager, RMSO |
| Dr Helen Cameron* | Consultant Obstetrician |
| Dr Liz Dillon | Consultant Radiologist |
| Dr Carole English | Cytogeneticist |
| Ms Jo Harcombe* | Regional Antenatal Screening Coordinator |
| Mr Bruce Jaffray | Consultant Paediatric Surgeon |
| Dr Bill Kirkup* | Regional Director of Public Health/Chair |
| Dr Heather Lambert | Consultant Paediatric Nephrologist |
| Dr Ruth Lawley | Consultant Obstetrician |
| Dr Mike McKean | Consultant Respiratory Paediatrician |
| Dr Judith Rankin | Principal Research Associate |
| Dr Sam Richmond | Consultant Paediatrician |
| Prof Steve Robson | Consultant in Fetal Medicine |
| Mrs Marjorie Renwick | Operational Manager RMSO |
| Mr John Scott | Retired Consultant Paediatric Surgeon |
| Dr Steve Sturgiss | Consultant in Fetal Medicine |
| Dr Martin Ward Platt | Clinical Director RMSO/Consultant Neonatologist |
| Prof John Wilkinson | Director North East PHO/**Chair** |
| Dr John Wolstenholme | Cytogeneticist |
| Dr Chris Wren | Consultant Paediatric Cardiologist |
| Dr Chris Wright | Consultant Perinatal Pathologist |

*Left group during 2004

## Multiple Birth (current)

| | |
|---|---|
| Dr Svetlana Glinanaia | Research Associate |
| Dr Judith Rankin | Principal Research Associate |
| Mrs Marjorie Renwick | Operational Manager RMSO |
| Dr Anne Ryall | Consultant Obstetrician |
| Dr Steve Sturgiss | Consultant Fetal Medicine |
| Dr Unni Wariyar | Consultant Paediatrician |
| Dr Chris Wright | Consultant Neonatal Pathologist/**Chair** |

## Diabetic Pregnancy Survey (current)

| | |
|---|---|
| Dr Maggie Blott | Consultant Obstetrician |
| Dr Tricia Cresswell | Director RMSO/Director of Public Health |
| Prof John Davison | Consultant Obstetrician/**Chair** |
| Mrs Lisa Doughty | Diabetic Specialist Nurse |
| Dr Gillian Hawthorne | Consultant Diabetologist |
| Dr Nick Lewis-Barnard | Consultant Diabetologist |
| Dr Judith Rankin | Principal Research Associate |
| Mrs Marjorie Renwick | Operational Manager RMSO |
| Dr Martin Ward Platt* | Clinical Director RMSO/Consultant Neonatologist |
| Mrs Val Williamson | Diabetic Midwife |
| Mr Rob Wood | Consultant Obstetrician |
| Dr W Lamb | Consultant Paediatrician |

*Left group during 2004

## NECCPS (current)

| | |
|---|---|
| Dr K N Agrawal | Consultant Paediatrician |
| Ms B Bilsbury | Children's Physiotherapist |
| Dr N Brewster | Consultant Paediatrician |
| M Bythell | RMSO Data Manager |
| Dr R Carpenter | Consultant Paediatrician |
| Dr A Colver | Consultant Paediatrician/ **Chair** |
| Dr N Cookey | Consultant Paediatrician |
| Dr J Dobson | Consultant Paediatrician |
| Dr M Gibson | Consultant Paediatrician |
| Dr C Jessen | Consultant Paediatrician |
| Dr A Johnston | Consultant Paediatrician |
| Dr E Lee | Consultant Paediatrician |
| Dr M Mans | Consultant Paediatrician |
| Dr R J Menzies | Consultant Paediatrician |
| Dr P Morrell | Consultant Paediatrician |
| Dr S K Pandy | Consultant Paediatrician |
| Dr S H Precious | Consultant Paediatrician |
| Dr K Whiting | Consultant Paediatrician |
| Ms V Wood | Children's Physiotherapist |

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