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NORTH EAST PUBLIC HEALTH OBSERVATORY

RMSO
REGIONAL MATERNITY SURVEY OFFICE

Northern Regional Maternity Survey Office
25th Annual Report 2006
including final data for 2005 and provisional data for 2006

December 2007

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KEY MESSAGES

1. Data are presented in this report at Local Authority (county and unitary) and maternity unit level. Summary mortality rates for the North East Region and the former Northern Region are on page iii.

2. The 1990s saw a fall in both the number of births and the crude live birth rate in this region as elsewhere and this continued until 2001 with a low of 29,059 total births. However, the total births for 2006 were again higher (32,660) than in 2005 (31,611) and 2004 (31,202). (Chapter 2)

3. The major contributor to perinatal deaths remains stillbirths occurring before the onset of labour (antepartum). A high proportion of these remain "unexplained". Of the 257 perinatal deaths in 2006, 129 (50.2%) were unexplained antepartum stillbirths. (Chapter 2)

4. The most important cause of infant mortality in 2006 was immaturity (37% of all infant deaths), followed by malformation (15.6%) and infection (14.4%). (Chapter 2)

5. A study assessing the long-term outcome of 107 babies born alive during 1990-92 with severe neonatal encephalopathy found mortality to be high with one third of babies dying during the neonatal period. Survivors of severe neonatal encephalopathy are at high risk of disability and by school age two thirds will either have died or have severe difficulties. (Chapter 2)

6. Post-mortem rates across the region remain at disappointingly low levels. Even for antepartum stillbirth the rate in 2006 was only 49%. The Human Tissue Act 2004 has significant implications for those discussing post-mortems with families and obtaining consent for the procedure. (Chapter 3)

7. There are approximately 550,000 children in the North East, around 29,000 births a year and only 231 child deaths (birth to 18th birthday). Nearly half of all child deaths occur in the first four weeks of life. Child deaths are therefore rare events, with individual causes of death being almost all statistically rare events. (Chapter 4)

8. Following extensive national consultation major changes have taken place with effect from January 2006 in the method of data collection for the Maternal Death Enquiry. (Chapter 4)

9. Data from the Northern Diabetic Pregnancy Survey show that women with pre-existing type 2 diabetes have similar outcomes of pregnancy as women with type 1 diabetes but are less likely to take folic acid before pregnancy, to have a caesarean section or to breast feed at birth. (Chapter 5)

10. Consensus regional standards on the care of mothers and their babies in pregnancies complicated by gestational diabetes have been developed. Data collection for all women with gestational diabetes will be piloted in a small number of maternity units in 2008. (Chapter 5)

11. The increase in birth rate in 2006 is not evenly distributed across the region. Measures of obstetrics intervention show significant variation in practice between comparable units handling a similar casemix. (Chapter 6)

12. Maternal obesity presents a number of challenges for maternity services. Important points to be considered when caring for these women are highlighted in chapter 7.

13. The twinning rate for 2006 (16.4 per 1,000 maternities) is higher than that reported for 2005 (14.9) and remains higher than that recorded for the years 1998 – 2001. (Chapter 8)

14. The prevalence of gastroschisis increased from 2.9 per 10,000 births in 2005 to 5.5 per 10,000 in 2006. Continued monitoring is needed to know whether this increase continues or not. (Chapter 9)

15. A total of 38 cases of sacrococcygeal teratoma, a rare sub-set of germ cell tumours, were identified from the NorCAS from 1985-2006, giving a total prevalence of 0.5 per 10,000 total births. Females are more affected than males, and overall 50% of the cases were detected antenatally using ultrasonography. (Chapter 9)

16. The rates of cerebral palsy among infants of 1000-1499g are falling. (Chapter 10)

17. The SPARCLE study (Study of Participation of Children with Cerebral Palsy living in Europe) showed that there is no overall difference in reported quality of life between children with cerebral palsy aged 8-12 years, who were able to report their own quality of life, and the general population of children at the same age. (Chapter 10)

SUMMARY MORTALITY RATES

North East Region and "Northern Region" 2005 (final), 2006 (provisional): Summary of perinatal and infant mortality data (RMSO) and number of births (ONS).
2005 and 2006 data for England & Wales (ONS)

	NORTH EAST REGION		NORTHERN REGION		ENGLAND & WALES	
	2005	2006	2005	2006	2005	2006
BIRTHS						
Total	28411	29340	31611	32660	649318	673203
Live	28247	29181	31429	32491	645835	669601
STILLBIRTHS						
Number	164	159	182	169	3483	3602
Rate (/1000 total births)	5.8	5.4	5.8	5.2	5.4	5.4
PERINATAL DEATHS						
Number	228	241	258	257	5180	5363
Rate (/1000 total births)	8.0	8.2	8.2	7.9	8.0	8.0
EARLY NEONATAL DEATHS						
Number	64	82	75	88	1697	1761
Rate (/1000 live births)	2.3	2.8	2.4	2.7	2.6	2.6
LATE NEONATAL DEATHS						
Number	26	29	27	31	530	584
Rate (/1000 live births)	0.9	1.0	0.8	1.0	0.8	0.9
POST-NEONATAL DEATHS						
Number	51	47	56	54	1032	1023
Rate (/1000 live births)	1.8	1.6	1.8	1.7	1.6	1.5
INFANT DEATHS						
Number	141	158	159	173	3259	3368
Rate (/1000 live births)	5.0	5.4	5.1	5.3	5.0	5.0

Note:

- The North East Region is the government office region and is coterminous with the North East Strategic Health Authority (2006).
- The "Northern Region" (1993 NHS boundaries) is the geographical area covered in 2006 by the North East Region plus "North Cumbria" (Allerdale, Carlisle, Copeland and Eden districts). Data are still presented to this boundary for historical continuity.

CONTENTS

1. INTRODUCTION

This report

This is the twenty-fifth annual report produced by the Regional Maternity Survey Office (RMSO). The aims of the report are:

- 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 is being used. There are also chapters on service delivery covering post-mortem and maternity care.

Key messages and recommendations are given on page (i) and summary mortality rates on page (iii).

The Regional Maternity Survey Office (RMSO)

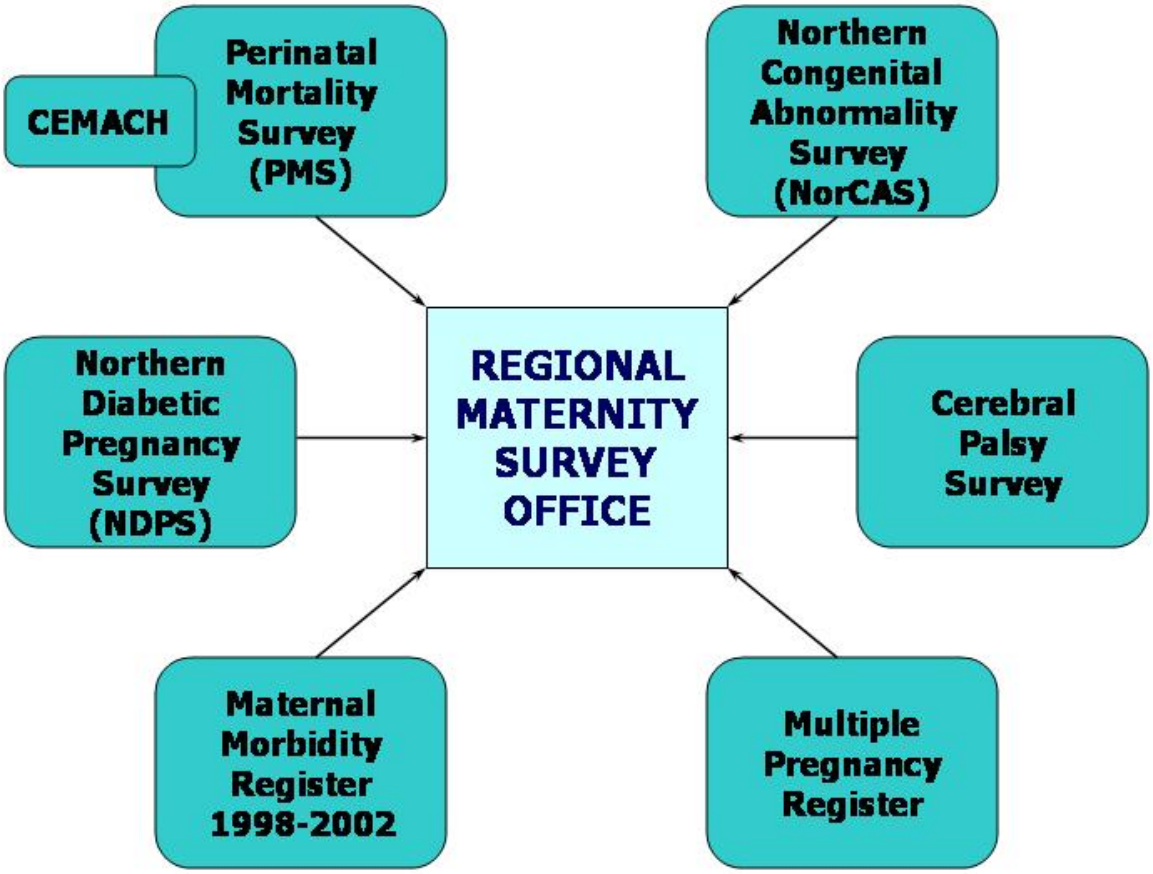
The Northern Regional Perinatal Mortality Survey (PMS) was established in 1981 with the aim of studying perinatal mortality and its causes. In 1985, the Fetal Abnormality Survey (now the Northern Congenital Abnormality Survey - NorCAS) was established with the remit of obtaining data on congenital abnormality in the Northern Region. From 1993, the RMSO delivered the regional coordination function for the national Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI), including both data collection and confidential enquiry panels. From April 2003, the RMSO has delivered these functions for the new Confidential Enquiry into Maternal and Child Health (CEMACH) which brought together 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). A survey of women with gestational diabetes will be piloted in 2008.

From January 2003, the RMSO has been the reporting route for the National Congenital Anomaly System (NCAS) and from 2004 has provided anonymised data to 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

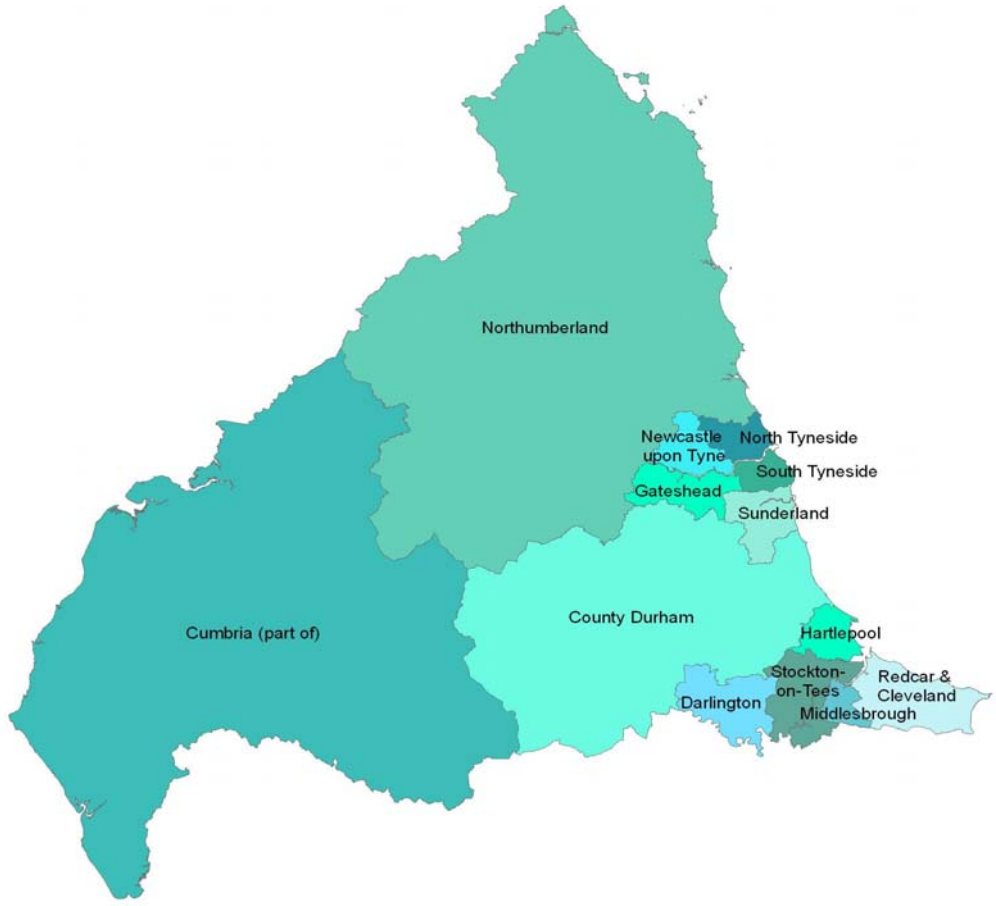


Boundaries for data collection and reporting

This is the fifth report produced by the RMSO since it became part of the NEPHO. Major changes occurred to NHS organisations in 2002, with the formation of Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs) and the abolition of Health Authorities and the NHS Regional Offices. On 1 July 2006 the two SHAs merged to form the North East Strategic Health Authority. On 1 October 2006 the number of PCTs in the North East Region reduced from 16 to 12, with the five County Durham PCTs merging to form one PCT and boundary changes to Middlesbrough and Langbaurgh PCTs to create a Middlesbrough PCT and a Redcar and Cleveland PCT. PCT populations continue to be defined as those registered with a General Practitioner in the PCT plus any unregistered population.

The RMSO has always reported data to consistent geographical boundaries as this is essential for comparison with national data sources. In this report, population data continues to be presented by Local Authority (map 1.1). However data for County Durham is presented at county level not district level (as has been the case for Northumberland for some years). Data at district level is available on request. Totals have always been presented for the former Northern NHS Region for continuity. Totals are also presented for the North East Region. The former Northern region comprises of the current North East Region plus four districts in 'North Cumbria' (Allerdale, Carlisle, Copeland and Eden).

Map 1.1: Unitary and county authorities covered by the RMSO



Northumberland County comprises of the districts of Alnwick, Berwick, Blyth Valley, Castle Morpeth, and Tynedale. Durham County comprises of the districts of Chester-le-Street, Derwentside, Durham City, Easington, Sedgefield, Teesdale and Wear Valley.

Consent and confidentiality

As a member of the British Isles Network of Congenital Anomaly Registers (BINOCAR), 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, Multiple Pregnancy Register and the NECCPS.

The RMSO Advisory Group was established in 2003 to address issues of consent and confidentiality in relation to the surveys. In 2007, this group was relaunched as the RMSO Steering Group (see Appendix 4 for membership). Data is processed at the RMSO within the parameters of the NEPHO *Security and Confidentiality Policy*[1], which incorporates an Annex relating to the RMSO. The RMSO is British Standard 7799 compliant. Access to data is tightly controlled.

[1] North East Public Health Observatory *Security and Confidentiality Policy.* At http://www.nepho.org.uk/view_file.php?c=495

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. A data request form should be completed and returned to the RMSO for all research projects even if the same data download is to be used. 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 publications involving data held by the RMSO is included in appendix 5.

RMSO funding

The RMSO currently has three main sources of funding:

- Funding on a capitation basis from the 12 North East PCTs;
- Department of Health disease registers grant to support NorCAS;
- CEMACH funding for its regional function for the North East.

The Department of Health (DH) grant for NorCAS has been extended by six months to October 2008. Additional funding continues to be sought. It is important that the RMSO is acknowledged in all publications and presentations, and that, where the paper has involved NorCAS data, the DH is also acknowledged. As part of the contract with the DH, all papers involving NorCAS data must be approved first by the DH before being submitted for publication. Please can you forward such papers to Judith Rankin who will liaise with the DH.

RMSO outputs

The surveys and registers are utilised:

- For local and regional audit in support of clinical governance in obstetrics, paediatrics, diabetes care and midwifery services across the region;
- For monitoring and evaluation of antenatal screening programmes;
- As a platform for research into causes of deaths, anomalies and disability and into service quality;
- As the regional component of national and international surveillance programmes.

The RMSO also provides the regional management function for CEMACH.

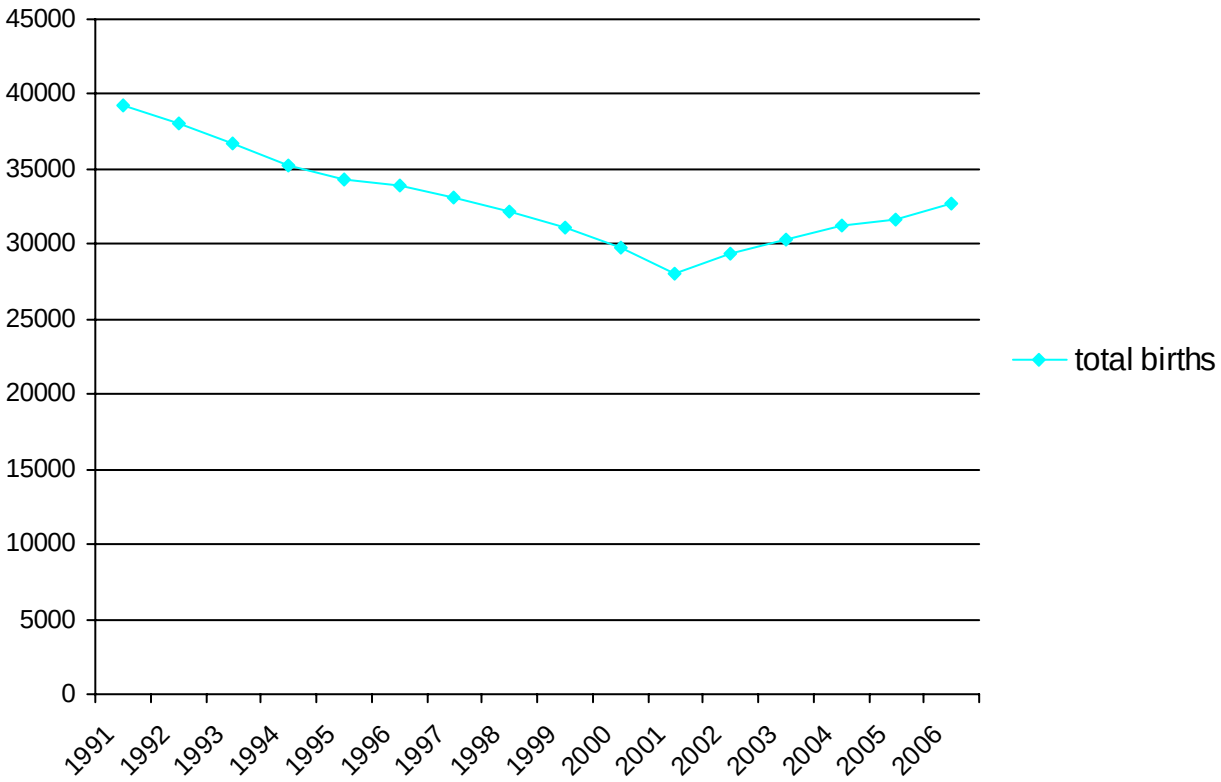
The RMSO provides regular feedback through this report and the annual meetings. There are annual meetings for four of the registers/surveys: PMS, NorCAS, NECCPS and the Northern Diabetic Pregnancy Survey (NDPS; see Appendix 2 for programmes). This year a meeting was held to showcase the data held by the Northern Multiple Pregnancy Register (MPR). This will now be an annual event. 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

Births

The 1990s saw a fall in both the number of births and the crude live birth rate in this region as elsewhere and this continued until 2001 with a low of 29,059 total births. However, the total births for 2006 were again higher (32,660) than in 2005 (31,611) and 2004 (31,202) as shown in figure 2.1.

Figure 2.1: Total Births 1991-2006 in the North East plus "North Cumbria"



Note the live birth data is obtained from the ONS. Totals vary slightly (average 10 per year in 30,000 births) from ONS published live births for the North East and North Cumbria due to changes in post code assignment and ward boundaries. Stillbirths are as reported to the RMSO (see Appendix 1).

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 (county, unitary and districts in 'North Cumbria') for the last three years. Some authorities show considerable year-to-year variation in perinatal mortality, which to a large extent reflects the relatively small number of deaths involved. In an attempt to overcome this, average perinatal mortality rates for the three year periods 2003-2005 and 2004-2006 are provided.

At least some of the variation in perinatal mortality between local authorities 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 2005 and 2006 and for 2003-2005 and 2004-2006. 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, local authority to local authority 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. 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.

Establishing an early warning system for perinatal deaths

In 2005, a system of routine monitoring of perinatal deaths was implemented. The RMSO continues to explore methods of monitoring perinatal mortality rates by unit, with the intention of creating a relevant early warning system to detect levels of perinatal death beyond that which would normally be expected. Units are alerted to unusually high rates as soon as possible so that assessment can be carried out and action taken, if appropriate, in a timely fashion.

Control charts are an effective and easily interpretable way to graph this sort of data as they allow deviations from the norm to be detected. The charts are now produced in Minitab. Annual perinatal mortality data for the region's maternity units in 2006 are shown in figure 2.2. Each data point represents a maternity unit, the centreline the expected number of perinatal deaths and the solid blue lines represent two and three standard deviation warning and control limits. The two sets of control limits represent 95% and 99.9% confidence limits, respectively. The data in figure 2.2 are all perinatal deaths booked and delivered at the same hospital in 2006, using 2006 births by unit as the denominator. All units fall within the control limits.

Until recently, all surveillance of perinatal mortality was carried out on cases booked and delivered at the same unit to adjust for transfers in utero to tertiary units. However, changes in maternity services mean that mothers are transferred during pregnancy for reasons other than those related to fetal medicine and these changes have meant that looking only at those cases booked and delivered at the same unit could give false

assurance for units who routinely refer mother to other units for delivery. Figure 2.3 shows perinatal deaths in 2006 by hospital booked using 2006 births by unit as the denominator.

Figure 2.2: 2006 perinatal deaths booked and delivered at the same hospital using 2006 births by unit as the denominator.

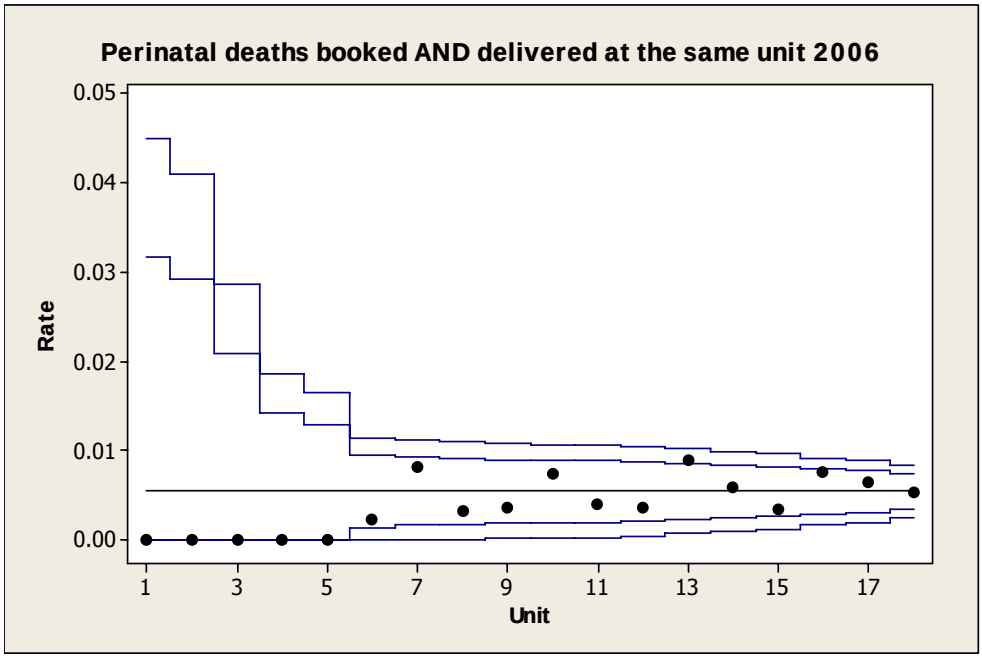
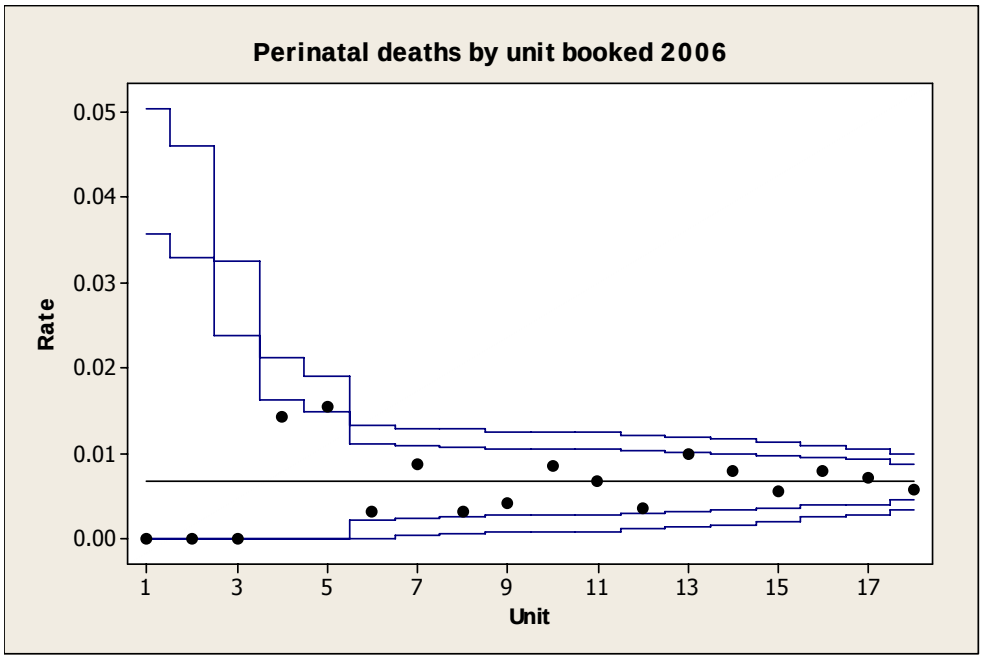


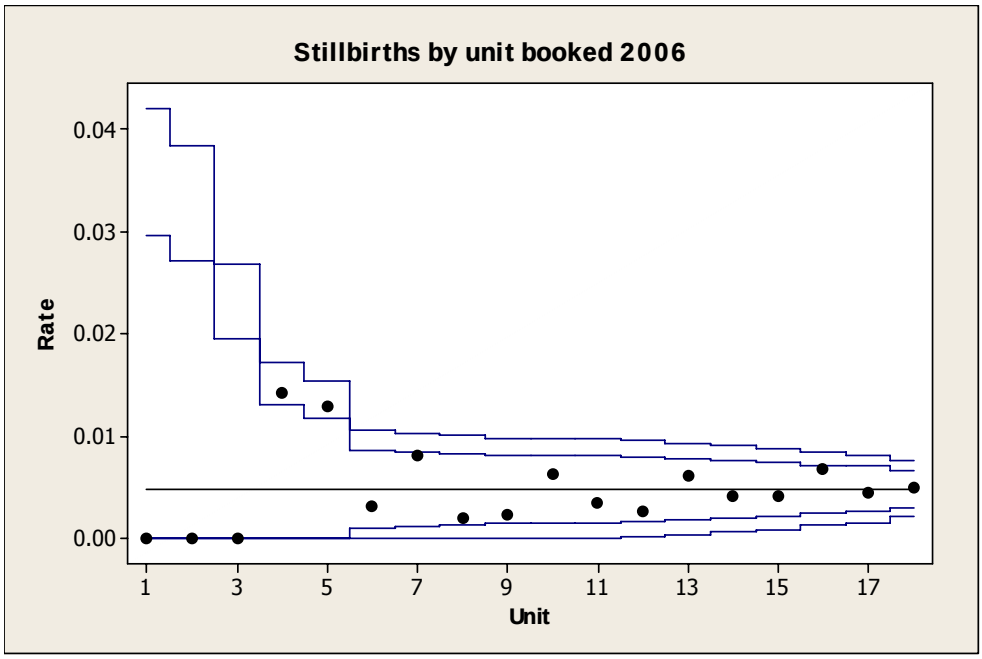
Figure 2.3: 2006 perinatal deaths booked at the same hospital using 2006 births by unit as the denominator.



Historically, stillbirths and neonatal deaths have been combined into a single measure of perinatal mortality. This not only minimised the variation in the classification of stillbirths

versus live births, but meant that the large proportion of neonatal deaths due to birth asphyxia were included in the figure. It has been argued that in developed countries, stillbirths and neonatal deaths should now be reported separately as the aetiology of stillbirths and neonatal deaths are more distinct, with birth asphyxia contributing to far fewer neonatal deaths than previously.[2] Figure 2.4 shows stillbirths by hospital booked using 2006 births by unit as the denominator.

Figure 2.4: 2006 stillbirths by hospital booked

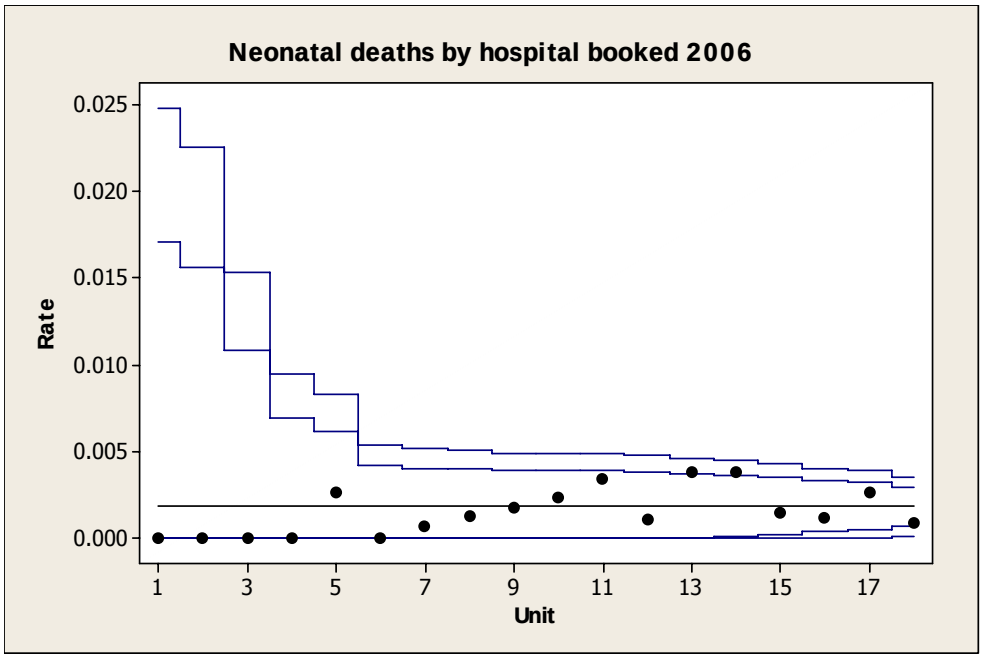


A provisional monitoring scheme was presented at the Perinatal Mortality Survey Annual Meeting in October 2007, which included monitoring cases booked and delivered at the same hospital as before, but also looking at all perinatal deaths and stillbirths by hospital of booking. In addition, as we continually refine the system, attempts to separate out neonatal deaths (Figure 2.5) from stillbirths will be undertaken, though it is acknowledged that these numbers are small and meaningful monitoring might not be possible.

Alerts are sent out to units when they fall outside of the two standard deviation warning limits or the three standard deviation control limits. Investigations can then be carried out by the units themselves. Weaknesses in this monitoring system include the inability to control for case mix and the usage of the previous year's number of births per unit for the denominator when the current year's births by unit are unavailable.

[2] Kramer MS, Liu S, Luo Z, et al, for the Fetal and Infant Health Study Group of the Canadian Perinatal Surveillance System. Analysis of perinatal mortality and its components: Time for a change? *American Journal of Epidemiology* 2002; 156: 493-96.

Figure 2.5: 2006 neonatal deaths by hospital booked



In summary, the RMSO continues to develop a system of monitoring deaths in the perinatal period that will allow for early action if necessary. Feedback from units is being sought to make the system as relevant and timely as possible.

Infant mortality

The total numbers of late abortions (20-23 weeks gestation), stillbirths, neonatal and post neonatal deaths for each local authority during 2005 and 2006 are presented in table 2.4, together with the calculated infant mortality rate (deaths in the first year of life/1,000 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" (50.2%), in the main unexplained antepartum stillbirth. Both congenital malformation and immaturity also contribute as significant causes.

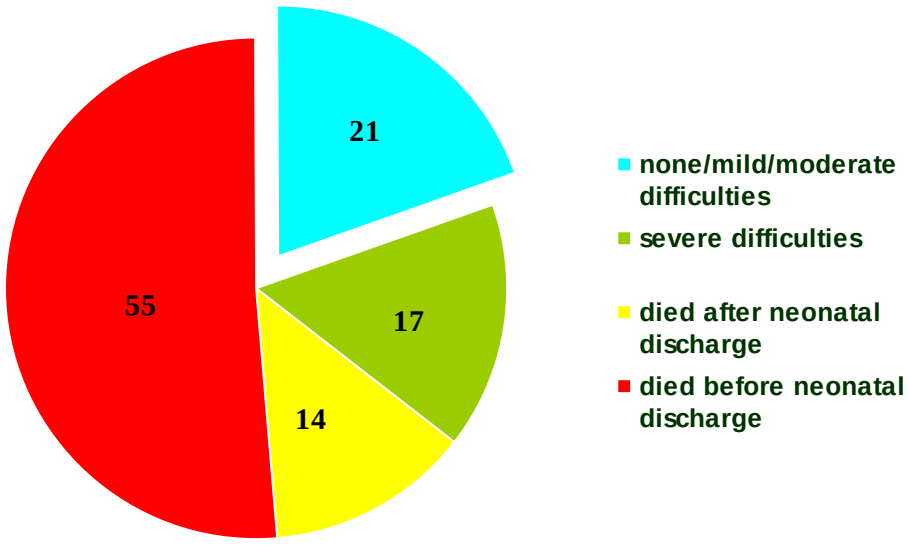
The most important cause of infant mortality in 2006 was immaturity (37% of all infant deaths), followed by malformation (15.6%) and infection (14.4%).

Intrapartum events: Morbidity in term and near term babies born in the Northern region, 1990-2004

Neonatal encephalopathy is a common cause of morbidity and mortality among term and near term babies. In the Northern region the rate of severe neonatal encephalopathy in term and near term babies has remained relatively unchanged from 0.9 per 1,000 live births in 1990 to 0.7 per 1,000 in 2004. A study led from James Cook University Hospital has followed up to school age 107 babies born alive during 1990-1992 with severe neonatal encephalopathy to assess long-term outcome.

Figure 2.6 shows the outcome for these 107 babies. Mortality is high with over half of babies born alive with this condition dying before neonatal discharge. Survivors of severe neonatal encephalopathy are at high risk of disability and by school age two thirds will either have died or have severe difficulties (Figure 2.6). Many of the children seen at follow up with severe difficulties were unable to sit supported, were blind and had no recognisable speech and could be described as having the developmental age of a child of three months.

Figure 2.6: Long-term outcome for 107 babies born alive during 1990-92 with severe neonatal encephalopathy.



Induced hypothermia may modify the outcome for some babies with neonatal encephalopathy. Results from a large UK multicentre study on total body cooling have yet to be published but other studies suggest that although induced hypothermia may be helpful for those with moderate encephalopathy, this is not the case for those in the severe category.[3] [4] In addition, recent reports in the literature have found that those babies who

[3] Shankaran S, Laptook A, Ehrenkranz RA, et al. Whole body hypothermia for neonates with hypoxic ischemic encephalopathy. *New England Journal of Medicine* 2005; 353 (13): 1574–84.

[4] Gluckman PD, Wyatt JS, Azzopardi D, et al. Selective head cooling with mild systemic hypothermia after neonatal encephalopathy: multicentre randomised trial. *Lancet* 2005; 365: 663-70.

have an Apgar score of zero at 10 minutes and who are successfully resuscitated have a very poor prognosis.[5] The International Liaison Committee on Resuscitation currently states in its guidelines on newborn resuscitation that "*if there are no signs of life after 10 minutes of continuous and adequate resuscitation efforts, it may be justifiable to stop resuscitation*".[6]

Therefore although making the decision to stop resuscitation in the delivery room can be a difficult one we must also consider that prolonging resuscitation may either delay death or result in the survival of a severely handicapped child.

[5] Harrington DJ, Redman CW, Moulden M, Greenwood CE. The long-term outcomes in surviving infants with Apgar zero at 10 minutes: a systematic review of the literature and hospital-based cohort. *American Journal of Obstetrics & Gynaecology* 2007; 196: e1-463.e5.

[6] The International Liaison Committee on Resuscitation. The International Liaison Committee on Resuscitation (ILCOR) consensus on science with treatment recommendations for pediatric and neonatal patients: neonatal resuscitation. *Pediatrics* May 2006; 117: e978 - e988.

Table 2.1: North East Region and Northern Region: Perinatal Deaths and Perinatal Mortality Rates 2004, 2005 & 2006 and 3 year rolling average Perinatal Mortality Rates 2003-2005 and 2004–2006, by Local Authority

Local Authority	Registered Total Births (ONS)			Number of Perinatal Deaths (PMS)			PERINATAL MORTALITY RATE (per 1000 Total Births)				
	2004	2005	2006	2004	2005	2006	2004	2005	2006	2003/05	2004/06
Hartlepool	1080	1122	1195	8	8	10	7.4	7.1	8.4	7.0	7.7
Stockton on Tees	2130	2251	2399	15	13	27	7.0	5.8	11.3	7.4	8.1
Middlesbrough	1857	1933	1886	12	20	13	6.5	10.3	6.9	8.2	7.9
Redcar & Cleveland	1519	1587	1538	15	13	15	9.9	8.2	9.8	8.6	9.3
Darlington	1263	1224	1290	12	9	15	9.5	7.4	11.6	7.1	9.5
County Durham	5376	5218	5431	43	46	49	8.0	8.8	9.0	8.8	8.6
Sunderland	2994	3093	3256	37	29	29	12.4	9.4	8.9	9.7	10.2
South Tyneside	1544	1533	1573	8	8	16	5.2	5.2	10.2	5.9	6.9
Gateshead	2136	2129	2258	12	22	16	5.6	10.3	7.1	8.3	7.5
North Tyneside	2173	2288	2263	19	18	9	8.7	7.9	4.0	7.7	6.8
Newcastle	2943	2998	3239	29	25	22	9.9	8.3	6.8	8.9	8.3
Northumberland	2966	3035	3012	14	18	20	4.7	5.9	6.6	5.9	5.8
NORTH EAST REGION	**27981**	**28411**	**29340**	**224**	**229**	**241**	**8.0**	**8.1**	**8.2**	**8.0**	**8.1**
Allerdale	888	902	895	5	9	7	5.6	10.0	7.8	6.7	7.8
Carlisle	1158	1113	1173	9	12	6	7.8	10.8	5.1	8.3	7.8
Copeland	693	726	775	5	4	1	7.2	5.5	1.3	8.5	4.6
Eden	491	459	477	2	4	2	4.1	8.7	4.2	8.5	5.6
NORTHERN REGION	**31211**	**31611**	**32660**	**245**	**258**	**257**	**7.8**	**8.2**	**7.9**	**8.0**	**7.9**

Note: The figures for 2004 and 2005 have been updated

Table 2.2: Northern Region 2005 & 2006: 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 2005 & 2006

Local Authority	Deaths known to RMSO								PERINATAL MORTALITY RATE			PERINATAL MORTALITY RATE		
	All perinatal Deaths		>499g only		>999g Only		Normally Formed >999g		All > 999g			Normally-formed > 999g		
	05	06	05	06	05	06	05	06	2005	2006	2004-06	2005	2006	2004-06
Hartlepool	8	10	7	10	6	8	5	8	5.3	6.7	5.3	4.5	6.7	4.7
Stockton on Tees	13	27	9	23	6	15	6	14	2.7	6.3	4.7	2.7	5.8	4.4
Middlesbrough	20	13	15	12	12	8	10	7	6.2	4.2	4.9	5.2	3.7	3.9
Redcar & Cleveland	13	15	10	15	10	6	9	5	6.3	3.9	5.6	5.7	3.3	5.0
Darlington	9	15	6	14	5	7	4	5	4.1	5.4	4.8	3.3	3.9	3.4
County Durham	46	49	40	42	27	27	23	26	5.2	5.0	5.2	4.4	4.8	4.6
Sunderland	29	29	24	25	15	14	15	13	4.8	4.3	6.0	4.8	4.0	5.6
South Tyneside	8	16	6	16	2	12	1	9	1.3	7.6	3.9	0.7	5.7	2.6
Gateshead	22	16	18	13	9	5	8	4	4.2	2.2	3.2	3.8	1.8	2.8
North Tyneside	18	9	16	8	12	5	11	5	5.2	2.2	3.7	4.8	2.2	3.1
Newcastle	25	22	22	19	16	15	14	14	5.3	4.6	5.4	4.7	4.3	5.0
Northumberland	18	20	15	17	9	15	8	14	3.0	5.0	3.7	2.6	4.6	3.3
NORTH EAST REGION	229	241	188	214	129	137	114	124	4.5	4.7	4.8	4.0	4.2	4.2
Allerdale	9	7	8	6	6	5	6	5	6.7	5.6	5.2	6.7	5.6	5.2
Carlisle	12	6	10	4	8	1	7	1	7.2	0.9	4.9	6.3	0.9	4.4
Copeland	4	1	3	0	2	0	2	0	2.8	0	2.3	2.8	0	1.8
Eden	4	2	4	2	3	1	3	1	6.5	2.1	3.5	6.5	2.1	2.8
NORTHERN REGION	58	257	213	226	148	144	132	131	4.7	4.4	4.7	4.2	4.0	4.1

Table 2.3: Northern Region 2005 & 2006: 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 some "non resident" births and some residents give birth in units outside the region.

Maternity Units	Registered Births		Stillbirths		ENND		LND		Non-Adjusted PNMR		Adjusted PNMR		Adjusted PNMR
	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2004-2006
Hartlepool	1678	1749	6	11	4	6	2	5	6.0	9.7	6.0	9.7	6.1
North Tees	2115	2139	10(2)	14	4(1)	11(4)	2	3	6.6	11.7	5.2	9.8	7.2
James Cook	3714	3843	28(1)	19(1)	7(1)	18(9)	5	3(2)	9.4	9.6	8.9	7.5	7.8
Guisborough	132	37	0	0	0	0	0	0	-	-	-	-	-
Darlington	2277	2389	14(5)	17(6)	5(2)	6	2	4	8.3	9.6	5.3	7.1	6.8
B. Auckland*	376	389	0	0	0	0	-	-	-	-	-	-	-
UHND Durham	2529	2715	17(1)	8(1)	3	5	3	1	7.9	4.8	7.5	4.4	6.1
Sunderland	3328	3413	23(1)	26(1)	7(2)	7(1)	2(1)	4(1)	9.0	9.7	8.1	9.1	9.4
S. Tyneside	1467	1483	3	12	2	1	1	0	3.4	8.8	3.4	8.8	5.0
Gateshead	1682	1772	8	5	6(2)	5	0	2	8.3	5.6	7.1	5.6	5.9
Newcastle	5176	5699	32(10)	37(10)	15(7)	12(9)	8(2)	5(1)	9.1	8.6	5.8	5.3	6.1
N. Tyneside	1762	1670	9	4	2	3(1)	1	1	6.2	4.2	6.2	3.6	6.0
Ashington	1934	1934	7	5	6	5	0	1	6.7	5.2	6.7	5.2	5.2
Berwick	20	31	0	0	0	0	0	0	-	-	-	-	-
Alnwick	62	38	0	0	0	0	0	0	-	-	-	-	-
Hexham	286	281	0	0	0	0	0	0	-	-	-	-	-
Carlisle	1735	1708	10	4(1)	6(2)	4	1	1	9.2	4.7	8.1	4.1	6.0
West Cumberland	1282	1319	8	4	2	2(1)	0	1	7.8	4.5	7.8	3.8	5.4
Penrith	84	89	0	0	0	0	0	0	-	-	-	-	-
Totals	**31639**	**32698**	**175**	**166**	**69**	**85**	**27**	**31**	**7.7**	**7.7**	**6.6**	**6.4**	**6.5**

* Bishop Auckland became a midwifery-led unit in May 2004

Table 2.4: North East Region and Northern Region: Timing of death by Local Authority 2005 & 2006. Infant Mortality rate by Local Authority 2005 & 2006 and for 2004-2006

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		
	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	04/06
Hartlepool	1122	1195	6	2	6	7	2	3	1	4	0	2	2.7	7.5	7.7
Stockton on Tees	2251	2399	10	6	10	15	3	12	3	4	2	1	3.6	7.1	5.2
Middlesbrough	1933	1886	4	10	17	8	3	5	3	1	7	1	6.7	3.7	5.1
Redcar & Cleveland	1587	1538	6	7	10	9	3	6	2	1	5	3	6.3	6.5	6.7
Darlington	1224	1290	6	5	5	8	4	7	1	2	2	4	5.7	10.1	6.6
County Durham	5218	5431	24	29	30	30	16	19	5	5	12	11	6.3	6.4	6.3
Sunderland	3093	3256	13	19	25	24	4	5	3	2	3	4	3.2	3.4	3.3
South Tyneside	1533	1573	4	5	4	12	4	4	1	1	2	5	4.6	6.4	5.2
Gateshead	2129	2258	5	15	12	7	10	9	2	3	2	6	6.6	8.0	6.7
North Tyneside	2288	2263	8	10	15	6	3	3	1	2	4	5	3.5	4.4	3.9
Newcastle	2998	3239	11	15	19	18	6	4	3	2	8	3	5.7	2.8	4.7
Northumberland	3035	3012	4	13	11	15	7	5	1	2	4	2	4.0	3.0	3.7
NORTH EAST REGION	**28411**	**29340**	**101**	**136**	**164**	**159**	**65**	**82**	**26**	**29**	**51**	**47**	**5.0**	**5.4**	**5.1**
Allerdale	902	895	2	4	7	4	2	3	0	0	2	2	4.4	5.6	4.8
Carlisle	1113	1173	12	7	6	4	6	2	1	0	1	1	7.2	2.6	5.5
Copeland	726	775	2	3	2	1	2	0	0	1	0	1	2.8	2.6	2.7
Eden	459	477	1	0	3	1	1	1	0	1	2	3	6.5	10.5	7.7
NORTHERN REGION	**31611**	**32660**	**118**	**150**	**182**	**169**	**76**	**88**	**27**	**31**	**56**	**54**	**5.0**	**5.3**	**5.1**

NOTES: *20-23 week TOP and late fetal loss.

Table 2.5: Northern Region. Immediate cause of perinatal and infant death, infant and perinatal mortality rates 2004-2006

CAUSE OF DEATH	PERINATAL MORTALITY			INFANT MORTALITY		
	Deaths 2006	Average rate 2003-2005	Average rate 2004-2006	Deaths 2006	Average rate 2003-2005	Average rate 2004-2006
Malformation	22	1.3	1.0	27	1.4	1.2
Antepartum death (unexplained)	129	3.9	4.1	2	0.05	0.04
Intrapartum anoxia/trauma	25	0.8	0.8	18	0.4	0.4
Immaturity	47	1.0	1.1	64	1.3	1.5
Infection (including NEC[a])	19	0.5	0.5	25	0.7	0.7
SIDS[b]	0	0.01	0.01	18	0.5	0.6
Accident-non IP trauma	0	0	0	2	0.05	0.05
Other specific causes	12	0.5	0.4	14	0.3	0.3
Unclassifiable	3	0.05	0.05	3	0.1	0.1
All Causes	**257**	**8.0**	**7.9**	**173**	**4.9**	**4.9**

NOTES: [a] NEC – necrotising enterocolitis
[b] SIDS – Sudden Infant Death Syndrome
[c] Specific antenatal causes so classified as "antepartum death" although registered as live births

3. POST-MORTEM RATES

Post-mortem rates

Post-mortem rates for the region and for individual units are presented in table 3.1 (page 22). The numbers and rates are calculated from the numbers of deaths within a unit, excluding deaths to mother's resident outside of the region.

Post-mortem rates by outcome in 2006 (Table 3.2) are similar to rates in 2005, except for a lower rate of post-mortems following antepartum stillbirths and late neonatal deaths (LNND).

Table 3.2: Post-mortem rates as a percentage of all deaths by timing of death

	Post-mortem rates (%)						
	Antepartum stillbirth	Intrapartum stillbirth	All stillbirth	Early NND	Late NND	All NND	Post NND
2001	58	45	57	41	50	44	57
2002	55	16	51	27	43	31	45
2003	51	47	51	41	41	41	65
2004	51	27	50	31	36	32	58
2005	55	33	53	33	63	41	57
2006	49	46	49	40	48	42	56

NB: Data for 2001-05 have been updated

The Human Tissue Act (2004): A quick guide for those taking post-mortem consent

The Human Tissue Act (2004) was introduced to regulate the removal, storage and use of cellular bodily material from living or dead individuals. The stimulus for this important piece of legislation was the 1999 enquiry into cardiothoracic surgery at Bristol Children's Hospital which led to the recognition that consent procedures for the retention of organs and other tissue at post-mortem were inadequate, causing distress for families and generating considerable media and political interest.

The following points about the Act are worth noting:

- it is wide-ranging and has implications for those ***taking consent*** for procedures involving the handling of 'cellular bodily material' (including surgery and post mortems), as well as those carrying out such procedures.

- '**cellular bodily material'** is defined as 'material...which consists of or includes human cells'. Gametes, hair and nail from living individuals are specifically excluded,

but applied strictly the Act surprisingly covers material such as urine and faeces, which inevitably contain some cells.

- **the Act requires persons removing, storing or using tissue for what are called 'scheduled purposes' to have authority to do so,** either because valid consent has been taken from an appropriate person, or because they have permission from a coroner. These 'scheduled purposes' include: determining a cause of death; transplantation; research; and education, audit, public health monitoring etc. Note that some of these purposes will apply to tissue from living as well as deceased individuals.

- an offence will have been committed if, **without valid consent**, a person ***either*** carries out an activity for which consent is required; ***or*** falsely represents to a person performing such an activity that there is appropriate consent when they know this to be false. So, in the latter case, someone commits an offence if they give a pathologist reason to believe that valid consent has been taken for a post-mortem examination when they know that it hasn't.

Following a perinatal loss, **all** families should have the opportunity to consider giving consent for a post-mortem: even if the cause of death seems clinically obvious, some parents may have their own reasons for wanting a post-mortem (for example, concerns about specific aspects of management; wanting to help others by adding to medical knowledge; etc). Factors which are important in determining whether any consent taken is **valid** will include:

- providing accurate information for the person (usually a parent) giving the consent;

- making sure that person understands the information and appreciates the consequences of giving consent;

- not putting them under pressure.

It follows from this that, for the consenting process to be adequate, the person taking consent for a post-mortem examination must understand why they are asking for it (i.e. what the value of a post-mortem will be for the family); what it will involve (the basic methods, including taking and retaining tissue samples for microscopy ('histology'), and reconstituting the body afterwards); and use the appropriate documentation (an information booklet for the family, and a request form for the pathologist, as well as the consent form). This implies that the member of staff involved should have had appropriate training and preferably will have attended a post-mortem themselves.

The Human Tissue Authority (HTA) has been set up to provide oversight, guidance, regulation and monitoring of the Act's implementation and to issue licences. Licences are needed by institutions (in particular hospitals) where individuals are removing tissue; storing bodies, specimens or other bodily material; or are undertaking post-mortems. Guidance has come from the HTA in a series of Codes of Practice covering a variety of topics, but particularly relevant to us are those relating to Consent (code 1), Post-mortem examinations (code 3) and Removal, storage and disposal of organs and tissue (code 5). With relevance to the above discussion about consent, code 3 points out that:

- those seeking consent…should be sufficiently senior and well-informed, with a thorough knowledge of the procedure.

- responsibility…should not be delegated to untrained or inexperienced staff.
- nurses and midwives may be trained to take on this particular role.
- consent is best obtained by a person with whom the relatives have established a relationship; and
- the hospital should have a named individual who can provide support and information to the bereaved if a post-mortem is required.

In summary, the Human Tissue Act 2004 has significant implications for those discussing post-mortems with families and obtaining consent for the procedure. As the HTA's Code of Practice 1 points out, these individuals '*should receive training and support in the implications and essential requirements of taking consent*.'

Table 3.1: Post-mortem rates by unit

UNIT	ALL DEATHS (late fetal deaths, stillbirths and infant deaths)								PERINATAL DEATHS							
	No. of Deaths		No. of Post-Mortems		Post- Mortem Rate (%)				No. of Deaths		No. of Post-Mortems		Post- Mortem Rate (%)			
	2005	2006	2005	2006	2003	2004	2005	2006	2005	2006	2005	2006	2003	2004	2005	2006
Hartlepool	16	29	11	19	44	27	69	66	10	17	7	13	46	0	70	76
North Tees	30	35	17	19	49	52	57	54	14	25	7	14	60	44	50	56
James Cook	59	61	30	24	35	52	51	39	35	37	13	10	15	57	37	27
Darlington	40	51	15	23	63	31	38	45	19	23	7	9	57	32	37	39
Bishop Auckland*	0	0	0	0	16	57	N/A	N/A	0	0	0	0	17	75	N/A	N/A
UHND Durham	41	29	18	16	35	66	44	55	20	13	8	7	31	47	40	54
Sunderland	52	64	32	36	75	52	62	56	30	33	19	19	67	50	63	58
South Tyneside	11	21	5	13	73	36	45	62	5	13	2	6	78	50	40	46
Gateshead	20	24	12	12	67	44	60	50	14	10	7	3	75	44	50	30
RVI Newcastle	85	95	40	52	44	49	47	55	47	49	21	23	47	52	45	47
North Tyneside	19	17	11	9	58	47	58	53	11	7	5	2	80	36	45	29
Wansbeck	18	20	8	13	48	67	44	65	13	10	4	6	44	62	31	60
Hexham	0	0	0	0	50	N/A	N/A	N/A	0	0	N/A	0	100	N/A	N/A	N/A
Carlisle	33	20	17	7	54	33	52	35	16	8	9	2	36	30	56	25
West Cumberland	16	15	6	4	38	43	38	27	10	6	4	0	40	33	40	0
Home	9	7	7	5	67	14	78	71	7	4	5	3	67	0	71	75
TOTALS	**449**	**488**	**229**	**251**	**51**	**48**	**51**	**52**	**251**	**255**	**118**	**117**	**48**	**45**	**47**	**46**

4. 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 child death review project;
- The maternal death enquiry.

CEMACH Child Death Review project

Introduction

The *Working Together*[7] guidance requires all Local Safeguarding Children Boards (LSCBs) to have in place processes for analysing **all** child deaths (birth to 18 years) and for responding to unexpected deaths in children by 2008. There are 12 LSCBs in the North East, one for each unitary and County level local authority. These are geographically coterminous with the PCTs from October 2006.

The Child Death Review feasibility project was carried out by the CEMACH in the South West, West Midlands and North East regions, Wales and Northern Ireland.

The Child Death Review project sought to obtain an overview of all child deaths from 28 days to 18th birthday over a one year period (2006). Core data on all child deaths identified in these regions was collected. The protocol is available on the CEMACH website.[8] Detailed multi-agency panel reviews have been conducted (between January and September 2007) on a subset of deaths with a focus on identifying preventable and avoidable factors. These reviews used a confidential enquiry methodology and anonymised cases from other regions were considered.

A report on case ascertainment for the project was published by CEMACH in October 2007.[9] A full report is due in April 2008.

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[7] HM Government. *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children.* http://www.everychildmatters.gov.uk/resources-and-practice/IG00060/

[8] www.cemach.org.uk

[9] CEMACH. *Child death review. Report on Case Ascertainment and Data acquisition.* October 2007 http://www.cemach.org.uk/getattachment/04159364-5025-49a2-a851-98801afb7b1a/Child-Death-Review---Case-Ascertainment-and-Data-A.aspx - In the CEMACH report the number of deaths notified by the "north east" includes all deaths occurring in the north east region plus "North Cumbria", i.e. includes non resident deaths.

This report for the North East:

- Describes the CEMACH process;
- Provides information on child deaths (28 days to 18th birthday) reported to the RMSO as part of the CEMACH Child Death Review project;
- Provides information on neonatal deaths (birth to 27 days) during the same 12 month time period.

CEMACH process

The RMSO manages the CEMACH process for the North East Region and North Cumbria and had a multi-agency steering group for the Child Death Project. The RMSO established a notification process with NHS bodies, Police, Coroners and others. Cases were entered onto the secure CEMACH national database at the time of notification and cases were randomised to enquiry (or not) at this stage.

Requests for core data sets[10] to be completed and requests for GP records were sent out immediately a notification was received. For the 2006 cases, the RMSO was notified of cases which had been randomised by the national process and full case notes were requested on these children. Case notes were fully anonymised (all identifying information in relation to the child and family removed, staff names removed and titles/grades retained, all unit identifiers removed). Anonymised notes were then sent to CEMACH central office for distribution to other regions for confidential enquiry i.e. regions did not review local cases.

The enquiry panel process for cases reviewed in this region was completed by September 2007.

Case reporting in the North East (28 days to 18th birthday)

1 September 2005 - 31 December 2005 (pre pilot phase)
This region had 45 deaths reported in this period.

1 January 2006 to 31 December 2006

- **120 deaths** were reported which had occurred in children resident in the North East region.
- Core data sets have been returned either by the hospital doctor caring for the child or by the GP where the death has occurred in the community.

Characteristics of the NE cases (28 days to 18th birthday)

This section provides a brief overview of the **120** NE resident cases reported between January to end December 2006. Table 4.1 and figure 4.1 show the age distribution, with 36% of deaths occurring under one year (babies under 28 days are excluded).

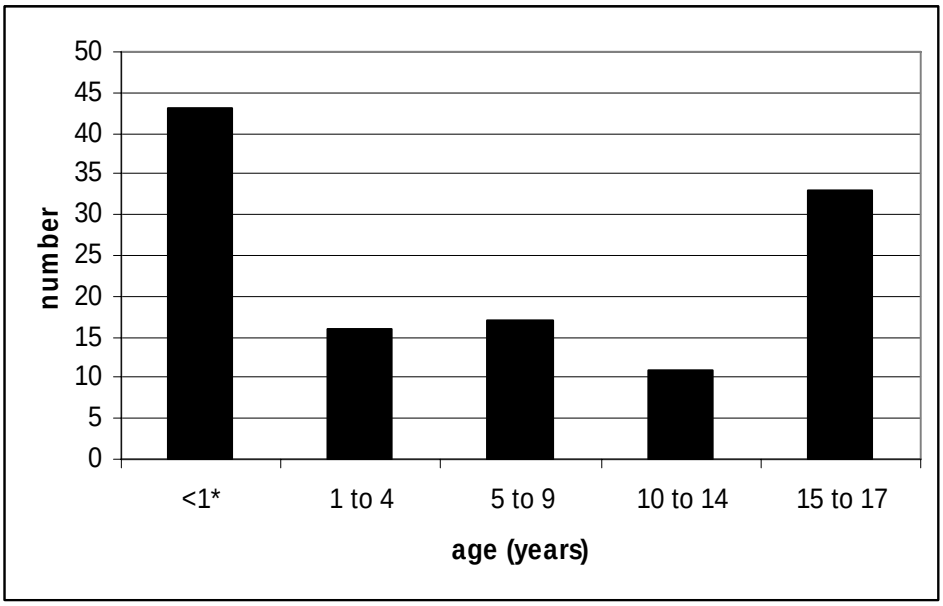
[10] http://www.cemach.org.uk/publications/Child%20Death%20Review%20Data%20Collection%20Form%20Final.pdf

Table 4 .1: Age distribution 28 days to 18th birthday

Age (years)	Number	Percentage
<1*	43	36%
1 to 4	16	13%
5 to 9	17	14%
10 to 14	11	9%
15 to 17	33	28%
Total	**120**	**100%**

* Note babies under 28 days are excluded

Figure 4.1: Age distribution (28 days to 18th birthday)



*Note babies under 28 days are excluded

The deaths are notified with a very wide range of possible causes, including rare medical conditions. For many of those classified as accident or suicide, the final coroner's findings are not available to the RMSO.

For this report, deaths have been assigned a provisional broad category based on the information in the core dataset (Table 4.2).

Table 4.2: Provisional categorisation of deaths 28 days to 18th birthday

Provisional category	Number of children
Road Traffic Accident (RTA)	12
Accident- other	9
Cancer	15
Cerebral palsy	5
Congenital abnormality	22
Epilepsy	<5
Infection	13
Non accidental injury	<5
Other/unknown	7
Prematurity	10
Substance misuse	<5
SUDI/SIDS	16
Suicide	<5
All categories	**120**

The terms Sudden Unexpected Death in Infancy (SUDI) and Sudden Infant Death Syndrome (SIDS) have been used interchangeably by some of those reporting deaths to the RMSO and are reported together here. The number of deaths categorised as SUDI will reduce following completion of investigations. SIDS should only be used as a final cause of death when all other possible causes of sudden unexpected death have been ruled out.

The commonest overall provisional categorisations are congenital abnormality and accidental (21 in total: 12 road traffic accident and nine accident – other) followed by SUDI.

There is a marked age variation in the provisional categorisation. Deaths categorised as accidental, suicide and cerebral palsy occurred mainly in older children/young people. Deaths categorised as "prematurity" as expected occurred in infancy. Most deaths related to congenital abnormality occurred in the early years.

Neonatal deaths in the North East (birth to 27 days inclusive)

The CEMACH project excluded babies under 28 days old as considerable work has already been done in relation to causes of these neonatal deaths. However data on neonatal deaths is collected by the RMSO as part of the longstanding regional Perinatal Mortality Survey with onward national reporting to CEMACH.

There were **111** neonatal deaths of babies born to mothers resident in the North East in 2006.

Characteristics of the neonatal deaths (birth to 27 days inclusive)

Neonatal deaths are classified in various ways. Table 4.3 gives a simplified version of the clinico-pathological classification system, applied to neonatal deaths in 2006. The majority of

neonatal deaths were due to prematurity, problems during labour, infection and congenital abnormalities. There are occasional unexpected deaths in apparently healthy babies under the age of 28 days (two in 2006) and these are investigated as Sudden Unexpected Deaths in Infancy.

CEMACH's predecessor organisation CESDI (Confidential Enquiry into Stillbirth and Deaths in Infancy) has undertaken a number of enquiries in relation to subsets of neonatal deaths and reports are available on the CEMACH website.

Table 4.3: Immediate cause of neonatal deaths (birth to 27 days inclusive), 2006

Immediate cause of death	Number of children
Congenital abnormality or disorder, including genetic disorders	11
Infection (including NEC[a])	13
Intrapartum anoxia/trauma (during birth and labour)	17
Prematurity	57
Other	11
SUDI/SIDS	2
All Causes	**111**

[a] NEC – necrotising enterocolitis

Next steps

- The RMSO is working with the LSCBs to establish a regional notification system for child deaths. From 1 April 2008, all LSCBs have a statutory duty to review child deaths (birth to 18th birthday).

- Work needs to be done to ensure that hospital based reviews of neonatal deaths are undertaken with a consistent approach across the region to facilitate reporting to the LSCBs.

Maternal deaths

It is a national requirement that all maternal deaths should be subject to confidential enquiry and all health professionals have a duty to provide the information required. In participating in the Confidential Enquiry, the professionals concerned are asked for three things:

(i) To provide a full and accurate account of the circumstances leading up to the woman's death, with supporting records;

(ii) To reflect on any clinical or other lessons that have been learned, either personally or as part of the wider institution; and

(iii) To describe what action may have followed as a result.

Aims and objectives of the maternal deaths enquiry (MDE)

The aim of the MDE is to help ensure that all pregnant and recently delivered women receive the best possible care delivered in appropriate settings and taking account of their individual needs.

The objectives are:

- To assess the main causes of and trends in maternal deaths;
- To identify any avoidable or substandard factors;
- To promulgate these findings to all relevant health care professionals;
- To improve the care that pregnant and recently delivered women receive and to reduce maternal mortality and morbidity rates still further, as well as the proportion of deaths due to substandard care;
- To make recommendations concerning the improvement of clinical care and service provision, including local audit, to purchasers of obstetric services and professionals involved in caring for pregnant and recently delivered women;
- To suggest directions for future areas of research and audit at a local and national level;
- To review methodologies for enquiry into maternal deaths.

Maternal Death Enquiry – 2006 onwards

Following extensive consultation major changes have taken place with effect from January 2006 in the method of data collection and completion of the maternal death enquiry book (MDR1). The following deaths should be reported to the CEMACH regional manager for the place of residence of the woman at the time of her death:

All Direct deaths

Direct deaths: Deaths during pregnancy or within 42 days of delivery, termination or abortion resulting from obstetric complications of the pregnant state (pregnancy, labour and puerperium), from interventions, omissions, incorrect treatment or from a chain of events resulting from any of the above e.g. thrombosis. This 42 day limit is an internationally recognised standard.

All Indirect deaths

Indirect deaths: Deaths during pregnancy or within 42 days of delivery, termination or abortion resulting from previous existing disease, or disease that developed during

pregnancy and which was not due to obstetric causes, but which was aggravated by the physiological effects of pregnancy e.g. cardiac disease.

Coincidental deaths

Coincidental (fortuitous): Deaths during pregnancy or within 42 days of delivery, termination or abortion from unrelated causes. The term 'coincidental' is now preferred to 'fortuitous' as being more appropriate and sensitive e.g. road traffic accidents.

In addition, the following deaths should be notified if they occur within six months of delivery, termination or abortion:

- *Direct* deaths (see definition above)
- Deaths due to peripartum cardiomyopathy
- Deaths due to suicide

Reporting the death

Deaths should be reported to the CEMACH regional manager as soon as possible after the death has occurred. It may also be helpful for you to take a photocopy of the notes at this stage for future reference (as notes are rarely available when you need them at a later date). Please telephone the regional office to notify them of the death. Have the woman's notes with you if possible. You will be asked for the following details of the woman:

Postcode and address
Date of birth
Date of death
Suspected cause of death
Place of death
GP name and contact details including post code and telephone number
Booking hospital
EDD
Date of delivery
Place of delivery
Pregnancy outcome
Obstetric consultant
Short details of the case

Within the next few days the regional office will then send you a MDR1 for completion.

Completing the MDR1 enquiry book

A letter will accompany the MDR1 giving details of any specific information required and the date for return of the MDR1 to the regional office. Where the place of death, place of booking and /or place of delivery were different from each other, the regional office will obtain the appropriate information independently from each place of care.

Page 2 of the MDR1 provides you with a checklist of the documentation required to enable the enquiry assessors to make a full and appropriate assessment of the factors leading up to and surrounding the death of the woman. Please send a photocopy of these records when returning the completed MDR1.

Pages 3-6 provide guidance for completion of the MDR1. If you haven't coordinated the completion of the MDR1 before please ensure you read this as it will ensure you provide the most appropriate details for this woman's type of death and minimise the need for the regional office to contact you for further information at a later date.

Sections 1-4 should be completed for all women – your regional office will agree with you whether you should be responsible for accessing GP information or whether they will take this responsibility on themselves.

Sections 5-16 should be completed as indicated in the checklist (page 2). **It is important that it is a clinician who was involved or has direct insight into the care of the woman who completes the MDR1** to ensure provision to the Enquiry of the most relevant information and also to allow for the 'self reflection' question to be answered. For example, if there was anaesthetic involvement in the case it should be an anaesthetist who completes section 13 of the MDR1.

Once the MDR1 is completed and all the requested documentation collated, including where relevant the local/trust serious untoward incident (SUI) review, please return to the regional office.

5. 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. NDPS collects data on pregnancy in women with pre pregnancy diabetes. The total number of pregnancies and the outcomes are shown in table 5.1.

Table 5.1: Outcome of Diabetic Pregnancies 1995-2006 (†Data for 2005 have been updated; data for 2006 are provisional)

Outcome	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005†	2006*
Women Registered	124	127	133	131	136	128	130	141	155	170	166	166
Live births	97	100	97	102	113	111	102	122	137	154	140	143
Sp. abort.<20 weeks gestation[1]	19	23	28	20	20	13	20	18	14	15	14	16
Sp. abort. 20–23+6 weeks gestation	0	1	3	0	0	0	0	0	0	0	2	2
Terminations	6	3	3	3	2	2	8	2	4	0	4	3
Antepartum Stillbirth	3	3	2	5	5	2	1	3	2	3	6	4
Intrapartum Stillbirth	0	0	1	1	0	0	0	0	0	0	1	0
Early Neonatal Death (0-6 days)	2	0	0	3	0	1	0	0	2	0	0	0
Late Neonatal Death (7-28 days)	2	0	1	0	0	0	0	1	0	0	0	0
Postneonatal Deaths (29-365 days)	0	0	0	0	1	1	0	1	1	2	0	3
Alive at 1 year	93	100	96	99	112	109	102	120	134	152	140	140
Total Outcomes	125[2]	130[3]	134[4]	131	140[5]	128	131[6]	145[7]	157[8]	172[9]	167[10]	168[11]
Perinatal Mortality Rate	50.0	29.1	30.0	83.3	42.4	26.5	9.7	24.0	28.8	19.1	47.6	27.2

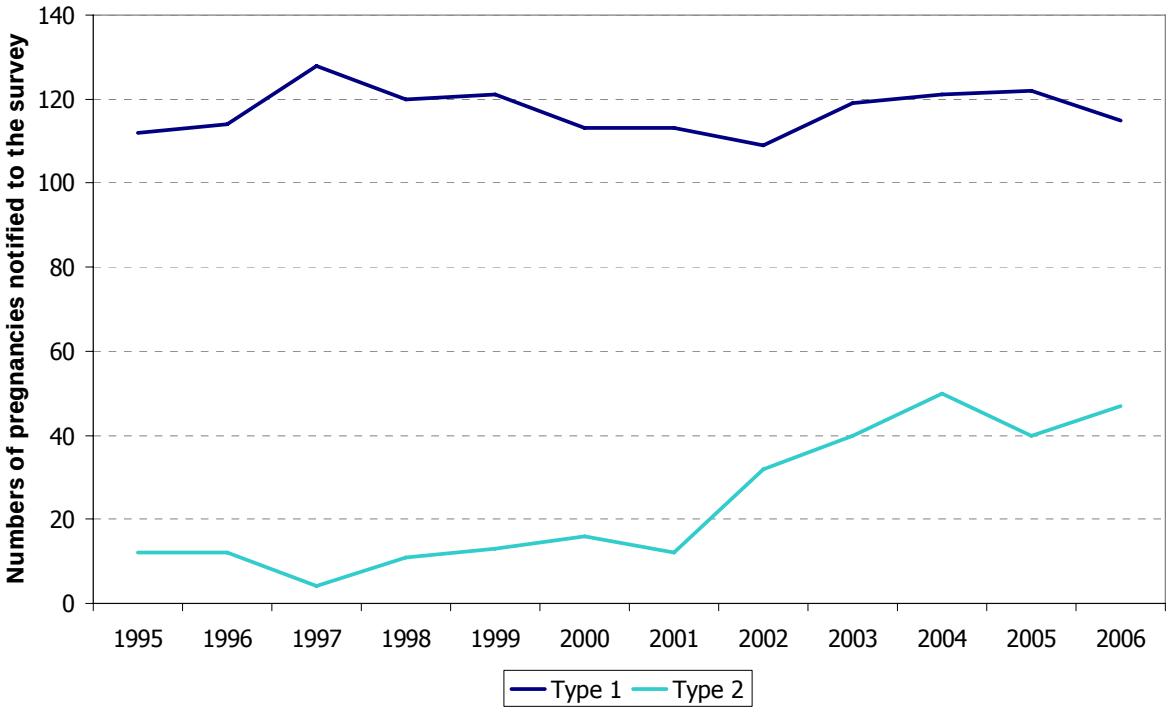
NOTES:
1. These figures underestimate pregnancy loss <20 weeks
2. 1 set of twins (2LB)
3. 3 set twins (2LB; 2LB; 1 LB+1 SB)
4. 1 set twins (2 miscarried)
5. 4 set of twins (all LB)
6. 1 set of twins (2LB)
7. 2 sets of twins (all LB), 1 set triplets (1 LND+1 PND+1 LB)
8. 2 sets of twins (all LB)
9. 2 sets of twins (all LB)
10. 1 sets of twins (2 LB)
11. 2 sets of twins (1 miscarried + 1 LB; 2LB)

Audit of pre-existing type 1 and type 2 diabetes

Diabetes is responsible for a significant burden of disease in the UK population and it is the most common pre-existing medical condition complicating pregnancy in this country. It is becoming more common, and its incidence is increasing in all age groups. Type 2 diabetes is being diagnosed more frequently in younger age groups including children and its prevalence is increasing. Pre-existing diabetes leads to additional risks in pregnancy for both the mother and the baby. Women with diabetes have an increased chance of their baby having a congenital anomaly, of losing the baby during pregnancy or at birth, or of the baby dying in infancy.

The observed pattern of a changing proportionate distribution of pre-existing type 1 and type 2 diabetes in pregnant women is also being seen in the Northern region, resulting in an increasing number of pregnancies in women with type 2 diabetes being reported to the NDPS (Figure 5.1). Rapidly increasing prevalence of obesity in all ethnic groups in the population, obesity occurring in younger people and a rise in age specific maximum fertility have been suggested as possible reasons.

Figure 5.1: Numbers of pregnancies with pre-existing diabetes notified to the survey, by type of diabetes, 1995-2006



Type 1 and type 2 diabetes have traditionally been managed differently, although a single set of service standards for the management of women with diabetes during pregnancy have been in use in the region since 1995. As the prevalence of type 2 diabetes in pregnancy has increased, and since data are now available for a 12 year period, we have reviewed whether women with pre-existing type 2 diabetes access and receive care in the same way as women with pre-existing type 1 diabetes, and compared their outcomes.

We audited 1407 pregnancies in women with pre-existing type 1 diabetes and 289 pregnancies in women with pre-existing type 2 diabetes with deliveries occurring in the period from 1st January 1995 to 31st December 2006. Characteristics of the women in the survey are shown in table 5.2.

Table 5.2: Characteristics of pregnant women with pre-existing type 1 and type 2 diabetes in the former Northern region, 1995-2006

Characteristic	Type 1 n/N	(%)	Type 2 n/N	(%)
Type of pregnancy				
Singleton	1390/1407	(98.8)	282/289	(97.6)
Twin	17/1407	(1.2)	6/289	(2.1)
Higher multiple	0/1407	(0)	1/289	(0.3)
Age at delivery				
<20 years	88/1407	(6.3)	3/240	(1.3)
20-29 years	684/1407	(48.6)	59/240	(24.6)
30-34 years	393/1407	(27.9)	76/240	(31.7)
35-39 years	197/1407	(14.0)	71/240	(29.6)
40+ years	45/1407	(3.2)	31/240	(12.9)
Median age [IQ range]	29 years	[24;33]	34 years	[29;37]
Parity				
0	521/1139	(45.7)	46/186	(24.7)
1	381/1139	(33.4)	49/186	(26.3)
2	157/1139	(13.8)	41/186	(22.0)
3 or more	80/1139	(7.0)	50/186	(26.9)
BMI > 30 Kg/m²	188/982	(19.1)	145/213	(68.1)
Smoker	314/1233	(25.5)	67/264	(25.4)
Ethnicity				
White	1340/1372	(97.7)	224/275	(81.5)
Other	32/1372	(2.3)	51/275	(18.5)
Total pregnancies	**1407**		**289**	

In summary women with type 2 diabetes, compared to women with type 1 diabetes, were more likely to be: older; on a second or subsequent pregnancy; obese at booking; and non-white – although the ethnic coding used within the survey needs to be reviewed.

All pregnancies, whether singleton, twin or higher multiple, were included in the analysis. Analysis was performed where data were available reflecting the agreed regional standards. The audit undertaken was based on the data submitted to the NDPS by the units and is purely

descriptive. The underpinning assumption for the audit is that women with pre-existing type 1 diabetes and women with pre-existing type 2 diabetes should receive the same standard of care, as outlined in the regional standards. We test this using odds ratios. Results are presented under the headings used within the regional standards.

Summary of findings

The following key messages from table 5.3 and figures 5.2 - 5.5 are for pregnancies to women with pre-existing type 2 diabetes compared to pregnancies to women with pre-existing type 1 diabetes:

- Have the same outcomes of pregnancy (risk of congenital anomaly, chance of a live birth).
- Are less likely to take folic acid before pregnancy (although this result was only statistically significant in the most recent years)
- Are equally likely to have their HbA1c measured during pregnancy, but more likely to be on target.
- Are equally likely to receive retinal screening, and more likely to receive antenatal fetal cardiac screening, once in care
- Are less likely to have a caesarean section, and more likely to have delivery at 39 or more weeks.
- Are less likely to breast feed at birth.

These findings are consistent with those from the CEMACH descriptive study[11] of 3808 pregnancies to women with diabetes in 2002-03, which showed that women with type 2 diabetes appeared to be less well prepared for pregnancy than women with type 1 diabetes, and to have an equivalent risk of adverse pregnancy outcome.

[11] Diabetes in Pregnancy: Are We Providing the Best Care? Findings of a National Enquiry: England, Wales and Northern Ireland. CEMACH. 2007.

Table 5.3: Results of audit against standards of care, by type of diabetes, for 1995-2006

Measure of Standard	Type 1			Type 2				OR (95% CI)	
	n	N	%	n	N	%			
Pre-pregnancy care									
HbA1c measured 3 months pre-pregnancy	675	1407	48.0	130	289	45.0		0.89	(0.69-1.14)
Folic acid before pregnancy	382	1407	27.1	66	289	22.8		0.79	(0.59-1.07)
Booked at less than 10 weeks	876	1407	62.3	176	289	60.9		0.94	(0.73-1.22)
Glucose monitoring and control									
HbA1c measured in T1	1107	1407	78.7	232	287	80.8		1.14	(0.83-1.57)
Achieving HbA1c <7% in T1	357	1407	25.4	121	287	42.2	*	2.14	(1.65-2.79)
HbA1c measured in T2	1113	1246	89.3	226	266	85.0	*	0.68	(0.46-0.99)
Achieving HbA1c <7% in T2	660	1246	53.0	177	266	66.5	*	1.77	(1.34-2.33)
HbA1c measured in T3	1058	1170	90.4	218	246	88.6		0.86	(0.53-1.28)
Achieving HbA1c <7% in T3	571	1170	48.8	147	246	59.8	*	1.56	(1.18-2.06)
Pregnancy screening									
Retina examined at booking	985	1407	70.0	211	289	73.0		1.16	(0.87-1.54)
Cardiac scan between 18 and 22 weeks	925	1246	74.2	216	266	81.2	*	1.50	(1.07-2.09)
Retina examined at 28 weeks	869	1170	74.3	193	246	78.5		1.26	(0.91-1.76)
Labour and delivery									
Induction of labour	501	1186	42.2	119	250	47.6		1.24	(0.94-1.63)
Caesarean section	736	1186	62.1	138	250	55.2	*	0.75	(0.57-0.99)
Delivery at 39 completed weeks or more	100	1170	8.5	32	246	13.0	*	1.60	(1.05-2.45)
Postnatal care									
Breast feeding at birth	431	1167	36.9	75	248	30.2	*	0.74	(0.55-0.99)
Breast feeding at discharge	376	1167	32.2	67	248	27.0		0.78	(0.57-1.06)
Admitted to special care	541	1167	46.4	68	248	27.4		0.75	(0.54-1.04)
Outcome measures									
Pregnancies affected by congenital anomaly	107	1407	7.6	20	289	6.9		0.90	(0.55-1.48)
Pregnancies resulting in live birth	1154	1407	82.0	242	289	83.7		1.13	(0.80-1.59)

NOTE: * denotes a statistically significant (at the 95% level) odds ratio

Figure 5.2: % taking folic acid pre-pregnancy

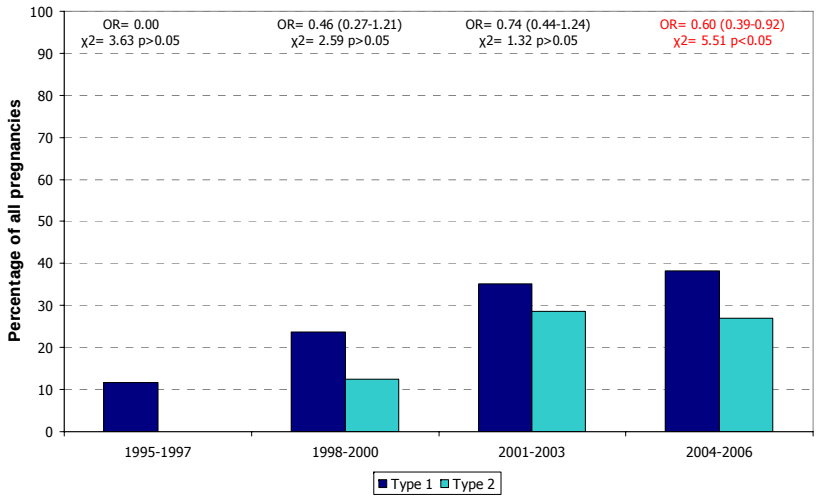


Figure 5.3: % with HbA1c of <7% in the first trimester

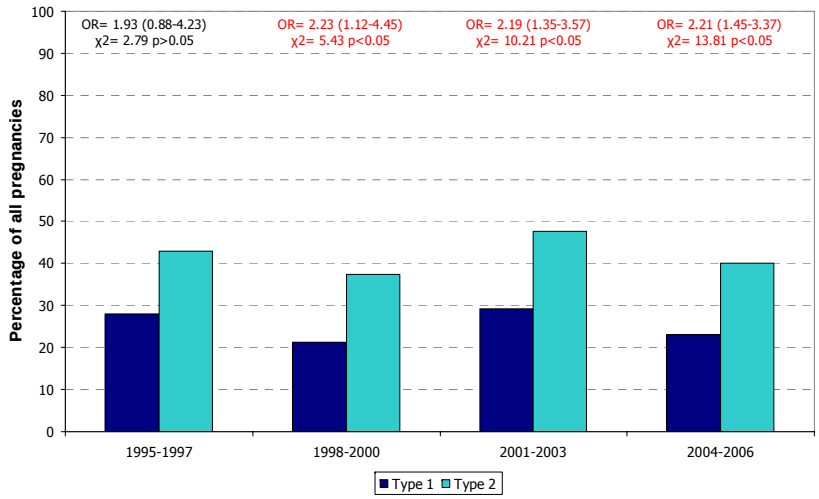


Figure 5.4: % admitted to SCBU

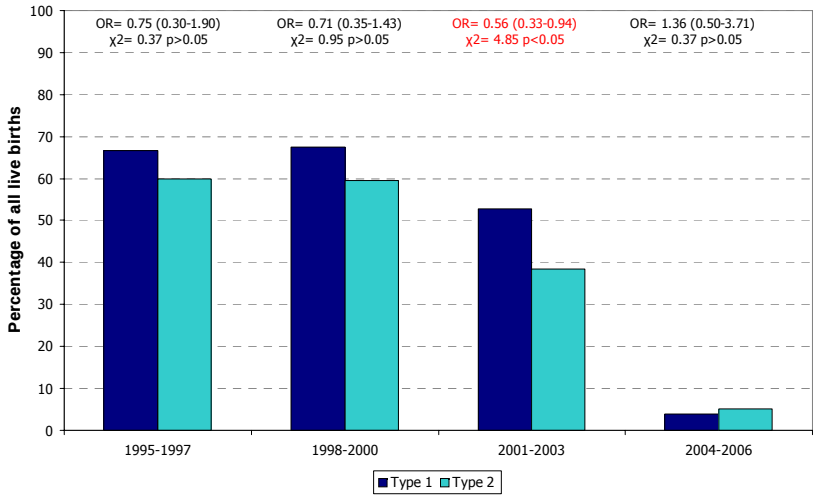
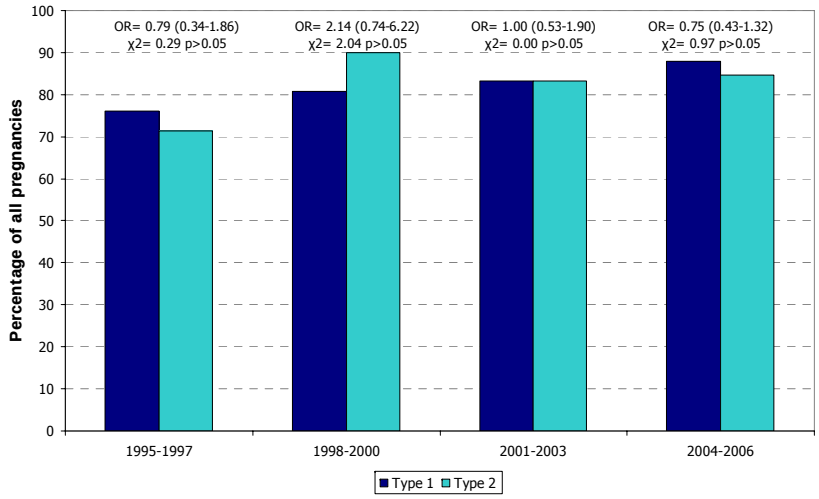


Figure 5.5: % resulting in at least one live birth



Gestational diabetes

Following a successful workshop in November 2006, broad agreement was reached on proposed regional standards for the diagnosis and management of gestational diabetes. The gestational diabetes working group met a number of times subsequently, to further refine the standards. The final draft was launched at the RMSO Summer Workshop on diabetes in pregnancy in July 2007. In October, NICE published draft guidance on diabetes in pregnancy[12] for consultation, with an anticipated final publication date of March 2008. The gestational diabetes working group is currently considering the implications for our new regional standards in the light of this national guidance.

Data collection for all women with gestational diabetes will be piloted in early 2008 in a small number of maternity units throughout the region, with a view to extending data collection region-wide. This will enable us to monitor trends in the diagnosis, process of care and outcomes of pregnancy for this important high risk group.

Publications involving NDPS data

- Bell R, Bailey K, Cresswell T, Hawthorne G, Critchley, J, Lewis-Barned N. Trends in prevalence and outcomes of pregnancy in women with pre-existing type 1 and type 2 diabetes. *BJOG: An International Journal of Obstetrics & Gynaecology* (in press).

- Improvements in pregnancy outcome for women with diabetes. In: *2006 Annual Report of the Chief Medical Officer*; Department of Health, 2007 (p.58).

[12] Diabetes in pregnancy (consultation). Draft NICE guidance, available at http://www.nice.org.uk/page.aspx?o=98537

6. MATERNITY CARE

Delivery statistics

The delivery statistics supplied by the individual units are shown in table 6.1. For the first time in over five years there has been a significant increase in the birth rate of almost 4%. This is not evenly distributed across the region. There was a large apparently endogenous increase of over 500 births within the Newcastle system with little evidence for surrounding units 'losing' deliveries into the city. All other units in the Region showed much smaller increases. Hexham and Bishop Auckland show here the first full year effects of their change to midwifery led care; their workload suggests stability following the change.

Measures of obstetric intervention once again show significant variation in practice between comparable units handling a similar casemix. It is difficult to consider how a more than two fold variation in the rates of assisted vaginal delivery could be justified with no obvious differences in outcome demonstrated.

The caesarean section rate is stable and below the national average. There is still large variation between units and again this represents a challenge to commissioners of service to question obstetric intervention. There has never been a time when more or better guidelines have been available for directing the way in which labour is managed and these variations remain very difficult to explain or justify.

One unusual finding this year relates to the incidents of twins. There has been a significant rise over recent years (see chapter 8); the factors behind this, aided fertilisation techniques and increasing maternal age, have been well documented elsewhere. There was a striking change however in South Cleveland where the number of twin deliveries has almost doubled. Even accounting for its role as a tertiary centre accepting in utero-transfers, this is difficult to explain. It will be interesting to monitor whether this represents a true change in the population over the coming years.

The Future

Although the region has seen significant changes in the move from consultant led to midwifery led deliveries, it is still difficult to see how the current service model can be maintained in the long-term. Pressures around the European working time directive, taken together with minimum standards for consultant led staff on labour ward, suggest that further changes will be required. As this report is being produced, the country is also in the middle of a significant review of a range of services led by the Minister for Health Lord Darzi. It seems likely that this will be a further driver for rationalisation of maternity services and it will be interesting to see the impact of its recommendations on current service configuration.

For the first time this year the survey attempted to gather data on in utero-transfers. This system failed as it is obvious that most units do not have a standard form for recording transfers in or out. We will do further work over the next year to try and gather data on this important subject.

We also tried to gather information on place of delivery for those women who were planning a home birth. Again there appears to be no standard format for recording this and in

particular no methods for tracking women who plan a home birth but who subsequently go on to deliver in hospital. Again we will try to produce a standard method to study this important group of women over the next year.

Table 6.1: Delivery Statistics supplied by units; figures in brackets are %

Unit	Maternities		Births		Twins**		Breech		Induction		Normal vertex delivery		Assisted		Caesarean section	
	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006	2005	2006
Hartlepool	1660	1738	1678	1749	18 (1.1)	18 (1.0)	70 (4.2)	71 (4.0)	365 (22.0)	400 (23.0)	1230 (74.1)	1220 (70.2)	97 (5.8)	121 (7.0)	342 (20.6)	396 (22.8)
North Tees	2084	2058	2115	2139	31 (1.5)	34 (1.6)	79 (3.7)	23 (1.1)	367 (17.6)	414 (20.1)	1457 (68.9)	1484 (72.1)	219 (10.4)	231 (11.2)	360 (17.0)	408 (19.8)
James Cook University Hospital	3649	3815	3714	3843	65 (1.8)	112 (2.9)	158 (4.3)	37 (9.6)	896 (24.6)	823 (21.6)	2645 (71.2)	2648 (69.4)	386 (10.4)	385 (10.1)	765 (20.6)	780 (20.4)
Darlington	2227	2365	2277	2382	38 (1.7)	37 1.6)	73 (3.2)	24 (1.0)	642 (28.8)	462 (19.5)	1474 (64.7)	1495 (63.2)	243 (10.7)	219 (11.4)	502 (22.0)	578 (24.4)
B. Auckland *	375	389	376	389	0	0	0	0	0	0	375 (99.7)	389 (100)	0	0	0	0
University Hospital of North Durham	2508	2705	2512	2715	47 (1.9)	30 (1.1)	84 (3.3)	12 (0.4)	574 (22.9)	605 (22.4)	1562 (62.2)	1728 (63.9)	394 (15.7)	372 (13.8)	565 (22.5)	606 (22.4)
Sunderland	3298	3384	3328	3413	49 (1.5)	46 (1.4)	113 (3.4)	125 (3.7)	548 (16.6)	576 (17.0)	2173 (65.3)	2324 (68.7)	401 (12.0)	419 (12.4)	588 (17.7)	557 (16.5)
S. Tyneside	1448	1463	1467	1483	19 (1.3)	20 (1.4)	54 (3.7)	6 (0.4)	368 (25.4)	353 (24.1)	945 (64.4)	1031 (70.5)	178 (12.1)	155 (10.6)	326 (22.2)	272 (18.6)
Gateshead	1649	1739	1682	1772	29 (1.8)	31 (1.8)	62 (3.7)	9 (0.5)	368 (22.3)	349 (20.0)	1069 (63.6)	1117 (64.2)	211 (12.5)	213 (12.3)	358 (21.3)	405 (23.3)
Newcastle RVI	5089	5585	5176	5699	87 (1.7)	111 (2.0)	194 (3.7)	216 (3.9)	808 (15.9)	1122 (20.1)	3200 (61.8)	3451 (61.8)	763 (14.7)	972 (17.4)	1019 (19.7)	1260 (22.6)
N. Tyneside	1740	1568	1762	1568	22 (1.3)	22 (1.4)	72 (4.1)	49 (3.1)	323 (18.6)	324 (20.6)	1308 (74.2)	1145 (73.0)	97 (5.5)	120 (7.7)	330 (18.7)	276 (17.6)
Wansbeck	1906	1911	1934	1934	28 (1.5)	23 (1.2)	80 (4.1)	9 (0.5)	350 (18.4)	348 (18.2)	1131 (58.5)	1187 (62.1)	322 (16.6)	275 (14.4)	449 (23.2)	444 (23.2)
Berwick	20	31	20	31	0	0	0	0	0	0	20	31 (100)	0	0	0	0
Alnwick	62	38	62	38	0	0	0	0	0	0	62	38 (100)	0	0	0	0
Hexham	286	281	286	281	1 (0.3)	0	11 (3.8)	13 (4.6)	0	0	219 (76.6)	243 (86.5)	1 (0.3)	0	64 (22.4)	38 (11.7)
Cumberland Infirmary, Carlisle	1714	1670	1735	1708	21 (1.2)	38 (2.3)	57 (3.3)	93 (5.6)	314 (18.3)	310 (18.6)	1220 (70.3)	1152 (69.0)	168 (9.7)	167 (10.2)	318 (18.3)	345 (20.7)
W. Cumberland Infirmary	1262	1302	1282	1319	8 (0.6)	17 (1.3)	44 (3.4)	44 (3.4)	207 (16.4)	243 (18.7)	840 (65.5)	925 (71.0)	138 (10.8)	133 (10.2)	284 (22.2)	272 (20.9)
Penrith	62	89	62	89	0	0	0	0	0	0	62 (100)	89 (100)	0	0	0	0
Total	31039	32131	27600	33552	463	539	1151	731	6130	6329	20992	21697	3618	3782	6270	6637

* Bishop Auckland Hospital became a midwifery lead unit in May 04; ** "Twins" is the number of women who delivered twins.

7. MATERNAL MORBIDITY

Maternal Obesity

Research has demonstrated that maternal obesity is associated with increased complications in pregnancy and delivery, and poses risks to both maternal and fetal welfare. The 6th Report on the Confidential Enquiry into Maternal Deaths highlighted that 35% of women who died during 2002-04 were obese.[13] The more recent CEMACH report found that more than half of the 231 women with known BMI who died during or after pregnancy during 2003-05 had a BMI>25 kg/m^2.[14] Indeed, 8% of these mothers were morbidly obese (BMI$\geq$ 40 kg/m^2). As obesity in pregnancy is increasing, this is a very worrying trend.

A recent scoping study drew attention to the dearth of national, regional or local statistics and the lack of evidence relating to the impact on maternity services.[15] This study found that some units in the region have had to change their criteria for consultant referral for women with a BMI> 30 kg/m^2 to BMI> 40 kg/m^2 as the units could not cope with the number of women being referred. The UK Obstetric Surveillance System (UKOSS)[16], based at the National Perinatal Epidemiology Unit in Oxford, is currently gathering data on extremely obese women (BMI> 50 kg/m^2).

Maternal obesity presents a number of challenges for maternity services. At present there are no national guidelines on the care of women who are obese in pregnancy. Kath Mannion, LSA Midwifery Officer for the North East region and Dr Helene Brandon, Consultant Obstetrician, have summarised some important points to be considered when caring for these women:

- It is essential that all women have their height and weight measured and recorded either at booking or during early pregnancy. Reliance on maternal estimations of weight and height may lead to an underestimation of the woman's BMI. This in turn may result in risk factors associated with increased BMI not being considered due to miscalculation.

- Women who are obese may lack vital nutrients such as folic acid and iron. This further increases the risk of ill health to both mother and baby. Obese women may need supplementation with increased amounts of folic acid to provide the same protection as lower levels do for non-obese women.

- Specialist scanning facilities also need to be considered as it is well recognised that there may be difficulties in scanning these women.

- Drug dosages for overweight and obese women need to be carefully calculated to ensure efficacy. This is particularly relevant for the calculation of anticoagulants used for thromboprophylaxis as obese women are at an increased risk of developing deep venous thrombosis and pulmonary embolism.

[13] Confidential Enquiry into Maternal Deaths. (2004) Why Mothers Die 2002-04. TSO, London.

[14] Lewis G (ed) 2007. The Confidential Enquiry into Maternal and Child Health (CEMACH). Saving Mothers' Lives: reviewing maternal deaths to make motherhood safer- 2003-05.

[15] http://www.nepho.org.uk/view_file.php?c=1263

[16] http://www.npeu.ox.ac.uk/UKOSS/index.php?content=EO.inc&mx='sub_menu'

- Equipment such as sphygmomanometers with large cuffs should be made available at every antenatal check to ensure that accurate blood pressure measurements are made. Using normal adult cuffs on obese women may lead to the blood pressure being calculated lower than it actually is and the diagnosis of pre eclampsia being missed. As maternal obesity is associated with increased risk and occurrence of pre eclampsia, early detection and appropriate management is essential to reduce the risk to the woman and her unborn baby.

- The lack of appropriate bariatric equipment such as theatre beds have been highlighted in previous CEMACH reports as placing women at risk. Suitable theatre tables and trolleys need to be available at all times for use to ensure that obese women and their babies are not placed at risk.

- Women who are obese have reduced choices in relation to care particularly around their choice of place of birth. Many midwifery led units have a restriction on booking women whose BMI is greater than 35 kg/m^2. Similarly waterbirth may not be available for women with BMI> 35 kg/m^2 due to concerns relating to moving and handling. This reduction in choice in place of birth means that these women have to give birth in high technology environments putting them at greater risk of operative delivery.

- The continuing focus on increasing breast feeding rates is also challenged by the rise in maternal obesity. It is well recognised that obese women have more difficulty in both initiating and maintaining breast feeding than women of normal weight. The benefits of breastfeeding are great as the key to prevention of obesity starts in childhood with breast fed babies having a reduced risk of obesity.

- All women regardless of size must be treated with dignity. Care planning needs to be sensitive and not alienate the woman and her family. Theatre wear including large gowns and scrub suits need to be available in order that partners are not excluded because of the lack of suitable clothing.

- Information around obesity needs to be discussed in a sensitive manner. Lifestyle changes and not quick fixes should be the order of the day and what better time to start that process than when women are pregnant and as such are a captive audience.

8. NORTHERN MULTIPLE PREGNANCY REGISTER

Introduction

The Northern Multiple Pregnancy Register (MPR) was set up in January 1998 to collect data on all multiple pregnancies arising in the Northern region. A total of 4339 twin pregnancies, 111 triplet pregnancies and nine higher order multiple pregnancies have been notified to the MPR during the nine years, 1998-2006. Table 8.1 shows the number of multiple pregnancies and twinning rates by year. The twinning rate apparently peaked in 2002 at 16.6 per 1000 maternities then decreased but appears to be rising again. These twinning rates compare with the rates of 9.8 per 1000 maternities in 1990 and 12.0 in 1994.[17]

Table 8.1. Numbers of multiple pregnancies and twinning rates, 1998-2006

	1998	1999	2000	2001	2002	2003	2004	2005	2006
Twin pregnancies	478	448	461	432	490	480	487	516	547
Twin maternities*	432	417	424	413	479	458	466	492	528
Triplet pregnancies	17	22	15	10	11	12	9	8	7
Higher order multiple pregnancies	2	1	1	2	0	1	0	1	1
TWINNING RATE / 1000 maternities	13.6	13.6	14.5	14.4	16.6	15.3	15.2	15.8	16.4
Total maternities	**31737**	**30652**	**29331**	**28718**	**28895**	**29849**	**30720**	**31102**	**32117**

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

The MPR has been very well supported throughout the region and continues to be unique in that it collects information on early losses and on chorionicity. We were recently invited by the journal *Twin Research & Human Genetics* to prepare a paper around the data held by the MPR over the past five years.[18] We present some of the results from it.

During 1998-2002, 2310 twin pregnancies were registered, with an increasing twinning rate of 13.6 to 16.6 per 1000 maternities. Chorionicity ascertainment in twin maternities with at least one stillbirth or live birth improved from 81% in 1998 to 91% in 2002. Before 24 weeks of gestation, 8.4% (359/4620) of fetuses were lost either spontaneously or as a result of termination of pregnancy. The perinatal mortality rate was much higher in monochorionic than dichorionic twins, mainly due to differences in stillbirth rates. The gestational-age-specific neonatal mortality rates were similar in twins and singletons, except

[17] Glinanaia SV, Rankin J, Renwick M. Time trends in twin perinatal mortality in the Northern Region of England, 1982-94. *Twin Research* 1998; 1: 189-95.

[18] Ward Platt M, Glinianaia SV, Rankin J, et al. The North of England Multiple Pregnancy Register: five-year results of data collection. *Twin Research & Human Genetics* 2006; 9: 913-18.

in the group of term births (≥37 weeks' gestation) when compared by conventional gestational age categories. For stillbirths, the rates were even lower than in singletons in gestational age categories of <32 weeks.

The register continues to be an important resource of data on multiple pregnancies, which allows monitoring of trends in multiple birth rates and pregnancy losses and provides a unique opportunity for aetiological and long-term follow-up studies.

Consent

In 2005, the MPR moved towards gaining patient consent in line with the Health and Social Care Act, 2001. Although consent has been returned for the majority of cases in which there were two live born twins, this has not always been the case when the pregnancy has resulted in other outcomes (i.e. miscarriage or single-twin demise). Cases cannot be put onto the MPR until consent is received. This means that currently case ascertainment is not complete, severely limiting the usefulness of the dataset. An application will be made to the Patient Information and Advisory Group (PIAG) for Section 60 approval to process data on early losses.

Relaunching the register

At a meeting of the Steering Group (see Appendix 4 for membership) in October 2006, it was decided that to fully maximise the potential of this register it would be necessary to relaunch it with a new clinical focus, whilst maintaining its epidemiological strengths. In line with this a half-day meeting took place in May 2007 to showcase which clinical issues can be addressed using data from the MPR (see Appendix 2 for programme). The meeting was very well received and generated a lot of interest in the MPR leading to the regeneration of the steering group to include input from more hospitals within the Northern region. A highlight of the day included a presentation on caring for couples with a multiple pregnancy by the Director of the Multiple Birth Foundation, Jane Denton. There were also very interesting and useful presentations by Dr Andrew Loughney, Sandra Bosman, Dr Judith Rankin, Dr Ruth Bell, Dr Brajagopal Ray and Dr Stephen Sturgiss. The issue of enhancing the provision and organisation of care for women with multiple pregnancies by using the register to audit their outcomes was discussed and work will continue on this throughout 2007 and 2008. The Steering Group are very appreciative of the considerable effort that local teams have put into the register, and would like to see this rewarded by the creation of a system that is clinically useful to all who contribute.

At a steering group meeting in July 2007 a new acronym was put forward for the MPR in line with its regeneration. The Register will now be known as NorSTAMP: **Nor**thern **S**urvey of **T**wins **a**nd **M**ultiple **P**regnancies. Work on making NorSTAMP a regional audit got underway at the meeting and will be continued at future meetings. It was decided that there will be a number of road shows around the region in 2007 and 2008 to iron out any difficulties with data collection and maintain motivation for NorSTAMP.

This is a very exciting time for NorSTAMP and we are confident the proposed changes will provide a more solid footing for this register and further enhance its national and international reputation.

Data summary

Below is some of the information available for each pregnancy for the last five years of data collection (2002-2006). The data for the years 1998-2001 can be found in previous annual reports.

In 2006, 352 (64.4%) twin pregnancies were detected before 13 weeks gestation, and 476 (87.1%) by 18 weeks (table 8.2).

Table 8.2. Gestation at diagnosis

Gestation at diagnosis (w)	2002 %	2003 %	2004 %	2005 %	2006 % (n)
<9	22.0	19.0	17.0	14.9	16.5 (90)
9-12	44.7	42.4	41.1	45.2	47.9 (262)
13-18	25.7	26.4	27.5	25.6	22.7 (124)
19-24	4.7	5.9	6.0	3.5	3.1 (17)
>24	1.2	0.7	1.2	1.9	1.5 (8)
not recorded	1.6	5.7	7.2	8.9	8.4 (46)

Among the 547 twin pregnancies in 2006, 53 fetuses (4.8%) were lost spontaneously before 24 weeks, there were 18 stillbirths (17 antepartum and 1 intrapartum), 21 early neonatal deaths, seven late neonatal deaths and three post neonatal deaths. The overall perinatal mortality rate was 36.9 per 1000 total twin births (44.7/1000 in 2005) and the infant mortality rate was 30.6 per 1000 live births (28.8/1000 in 2002; see table 8.3).

Table 8.3. Mortality data for 2002-2006

	2002 %	2003 %	2004 %	2005 %	2006 %
Losses <24w (all pregnancies)	4.0	4.6	5.3	4.8%	4.8%
Stillbirths (n)	22	17	16	26	18
Early NND (n)	19	12	7	18	21
Late NND (n)	6	3	5	4	7
PNMR (/1000 total births)	42.8	31.7	24.7	44.7	36.9
Infant mortality (/1000 live births)	31.6	20.8	17.9	28.8	30.6

The mode of delivery for both twins (528 maternities) is summarized in table 8.4. Section rates for twin 1 and twin 2 are lower than that recorded in 2005.

Table 8.4. Mode of delivery by year

Mode of delivery	2002		2003		2004		2005		2006	
	Twin 1 (%)	Twin 2 (%)	Twin 1 (%)	Twin 2 (%)	Twin 1 (%)	Twin 2 (%)	Twin 1 (%)	Twin 2 (%)	Twin 1 (%)	Twin 2 (%)
Normal	35.9	22.5	31.9	19.9	32.2	20.2	28.3	18.7	28.2	18.2
Forceps	5.0	2.9	3.1	4.4	4.1	2.4	3.0	2.2	4.2	2.5
Ventouse	5.6	4.2	5.5	3.1	5.2	3.2	4.3	3.9	3.2	3.4
Breech	1.3	10.6	4.6	13.1	0.6	11.4	2.0	10.0	2.1	11.2
Section	50.5	51.8	51.1	51.3	48.3	51.1	43.7	45.9	40.7	42.2
Other	0	0	0	0	0	0	0	0.2	0.4	0.4
Unrecorded	1.7	7.9	3.9	8.3	9.7	11.8	18.7	19.1	21.2	22.2
TOTAL	100	100	100	100	100	100	100	100	100	100

Publications involving NorSTAMP data since 2004

- Ward Platt M, Glinianaia SV, Rankin J, Wright C, Renwick M. The North of England Multiple Pregnancy Register: five-year results of data collection. *Twin Research & Human Genetics* 2006; 9: 913-18.

9. NORTHERN CONGENITAL ABNORMALITY SURVEY

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.

Table 9.1 reports the number and total prevalence rate per 10,000 registered births for selected congenital anomalies by year for the five years 2001-2005. As NorCAS is an active survey and includes cases notified at any time until age 12 years, the figures may be slightly different from those given in previous annual reports. Figure 9.1 shows the trends in total prevalence over time for neural tube defects and component subtypes, and figure 9.2 summarises the secular trends in total prevalence for the three main trisomies 13, 18 and 21.

Register Developments

Data sharing

ONS - Data notification from NorCAS to the National Congenital Anomaly System, (NCAS) operated by the Office for National Statistics (ONS), began in January 2003. As a result of the reorganization programme within ONS, NCAS is now run out of Newport, Wales and headed by Vera Ruddock.

EUROCAT - NorCAS is a full member of the European Surveillance of Congenital Anomalies (EUROCAT), a network of European congenital anomaly registers from 31 countries.[19] NorCAS has now contributed six years of data (2000-2005). NorCAS is currently involved in the following EUROCAT projects;

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

Table 9.1 Number and total prevalence rate for selected congenital anomalies notified to NorCAS, 2001-2005*#.

Anomaly Subgroup	2001		2002		2003		2004		2005		Total	
	No.	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*
Nervous system	91	31.3	82	27.9	90	29.7	67	21.5	91	28.8	421	27.6
Neural tube defects	45	15.5	35	11.9	51	16.8	36	11.5	47	14.9	214	14.0
Anencephaly	16	5.5	12	4.1	23	7.6	15	4.8	20	6.3	86	5.6
Encephalocele	2	0.7	3	1.0	5	1.7	1	0.3	7	2.2	18	1.2
Spina bifida	27	9.3	20	6.8	23	7.6	20	6.4	20	6.3	110	7.2
Hydrocephaly	18	6.2	19	6.5	19	6.3	10	3.2	23	7.3	89	5.8
Eye	13	4.5	7	2.4	9	3.0	11	3.5	8	2.5	48	3.1
Ear, face and neck	1	0.3	4	1.4	3	1.0	4	1.3	2	0.6	14	0.9
Congenital heart disease	262	90.2	326	110.9	373	123.0	292	93.6	304	96.2	1557	102.0
Common arterial truncus	2	0.7	4	1.4	6	2.0	1	0.3	5	1.6	18	1.2
Transposition of great arteries	14	4.8	8	2.7	17	5.6	17	5.5	13	4.1	69	4.5
Ventricular septal defect	141	48.5	151	51.4	179	59.0	125	40.1	135	42.7	731	47.9
Atrial septal defect	51	17.6	79	26.9	79	26.1	64	20.5	55	17.4	328	21.5
Atrioventricular septal defect	18	6.2	17	5.8	24	7.9	25	8.0	24	7.6	108	7.1
Tetralogy of Fallot	12	4.1	22	7.5	16	5.3	16	5.1	15	4.8	81	5.3
Tricuspid atresia and stenosis	0	0.0	1	0.3	3	1.0	4	1.3	3	1.0	11	0.7
Pulmonary valve stenosis	22	7.6	46	15.7	43	14.2	41	13.1	44	13.9	196	12.8
Aortic valve atresia/stenosis	9	3.1	10	3.4	12	4.0	4	1.3	13	4.1	48	3.1
Hypoplastic left heart	7	2.4	6	2.0	5	1.7	8	2.6	7	2.2	33	2.2
Coarctation of aorta	17	5.9	16	5.4	14	4.6	22	7.1	13	4.1	82	5.3
Respiratory	13	4.5	16	5.4	24	7.9	19	6.1	11	3.5	83	5.4
Oro-facial clefts	49	16.9	47	16.0	65	21.4	50	16.0	61	19.3	272	17.8
Cleft lip with or without palate	33	11.4	29	9.9	36	11.9	31	9.9	37	11.7	166	10.9
Cleft palate	16	5.5	18	6.1	29	9.6	19	6.1	24	7.6	106	6.9

Anomaly Subgroup	2001		2002		2003		2004		2005		Total	
	No.	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*
Digestive system	55	18.9	44	15.0	53	17.5	41	13.1	62	19.6	255	16.7
Oesophageal atresia with or without fistula	9	3.1	8	2.7	7	2.3	4	1.3	12	3.8	40	2.6
Duodenal atresia or stenosis	4	1.4	11	3.7	4	1.3	6	1.9	7	2.2	32	2.1
Ano-rectal atresia and stenosis	13	4.5	11	3.7	13	4.3	9	2.9	8	2.5	54	3.5
Diaphragmatic hernia	14	4.8	15	5.1	8	2.6	10	3.2	12	3.8	59	3.9
Urinary	118	40.6	81	27.6	106	35.0	102	32.7	82	25.9	489	32.0
Bilateral renal agenesis	7	2.4	3	1.0	10	3.3	6	1.9	3	1.0	29	1.9
Cystic kidney disease	18	6.2	15	5.8	26	8.6	23	7.4	23	7.3	105	6.9
Congenital hydronephrosis	43	14.8	23	7.8	35	11.5	23	7.4	18	5.7	142	9.3
Limb	31	10.7	37	12.6	44	14.5	38	12.2	30	9.5	180	11.8
Upper limb reduction	9	3.1	11	3.7	12	4.0	15	4.8	12	3.8	59	3.9
Lower limb reduction	9	3.1	2	0.7	4	1.3	6	1.9	6	1.9	27	1.8
Abdominal wall defects	20	6.9	23	7.8	33	10.9	35	11.2	24	7.6	135	8.8
Gastroschisis	11	3.8	8	2.7	20	6.6	23	7.4	9	2.8	71	4.7
Exomphalos	9	3.1	14	4.8	10	3.3	12	3.9	14	4.4	59	3.9
Musculo-skeletal	25	8.6	31	10.6	30	9.9	30	9.6	26	8.2	142	9.3
Chromosomal	138	47.5	129	43.9	126	41.5	146	46.8	136	43.0	675	44.2
Down's syndrome	64	22.0	74	25.2	58	19.1	83	26.6	60	19.0	339	22.2
Patau syndrome (trisomy 13)	6	2.1	3	1.0	9	3.0	8	2.6	11	3.5	37	2.4
Edward's syndrome (trisomy 18)	12	4.1	10	3.4	22	7.3	23	7.4	24	7.6	91	6.0
Turner's syndrome	14	4.8	7	2.4	9	3.0	5	1.6	11	3.5	46	3.0
Klinefelter's syndrome	3	1.0	2	0.7	3	1.0	2	0.6	1	0.3	11	0.7
Total no. of births	29060		29394		30329		31202		32660		152645	

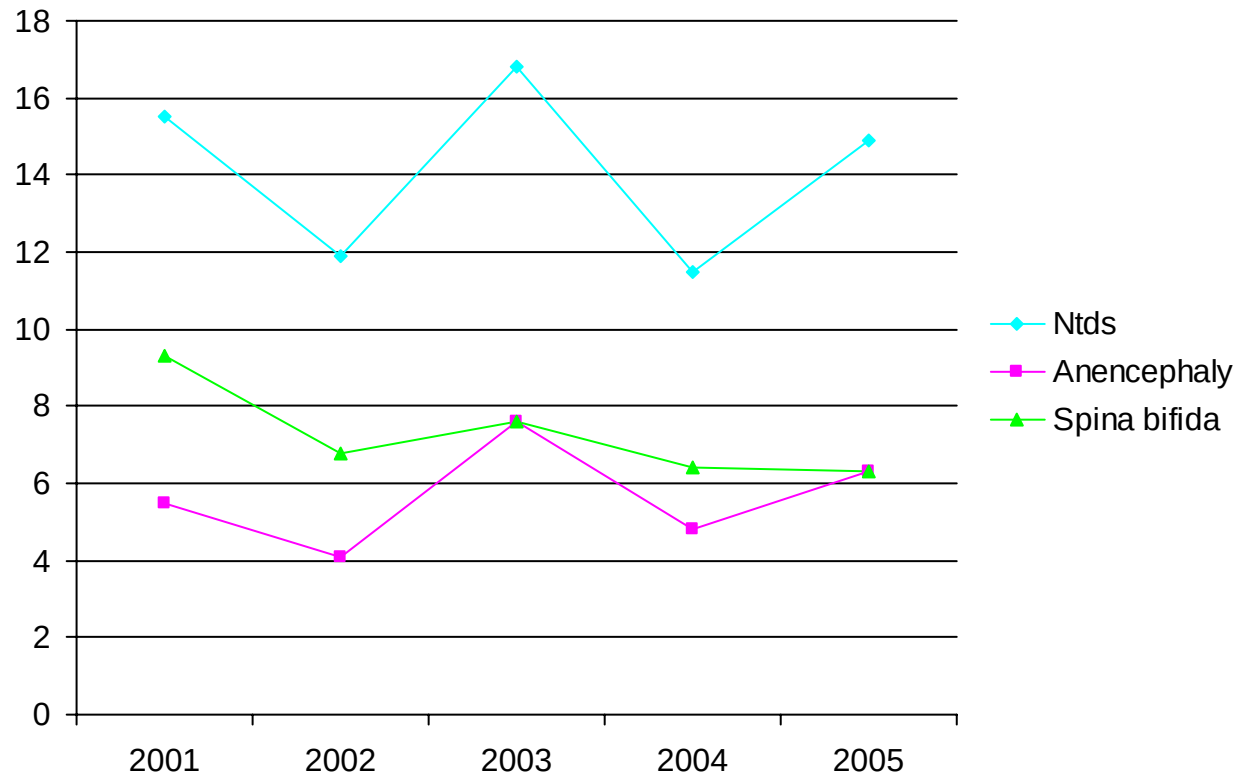
* Number of cases occurring in live births, stillbirths, miscarriages after 20 weeks gestation and terminations of pregnancy for fetal anomaly

#Numbers may be different from that reported last year due to additional cases being notified

- Epidemiology of selected rare syndromes in Europe
- Prevalence and surveillance of sentinel phenotypes in Europe
- Twin study: ischaemia aetiology leading to 'vanishing twin'
- Perinatal mortality due to congenital anomalies
- Arthrogryposis multiplex congenital – cause and risk factors
- Risk of recurrence in Down's syndrome: sibling risks
- Maternal diabetes and congenital anomalies
- Study on eye malformations
- Prenatal diagnosis and outcome of pregnancy of specified sex chromosome abnormalities in Europe

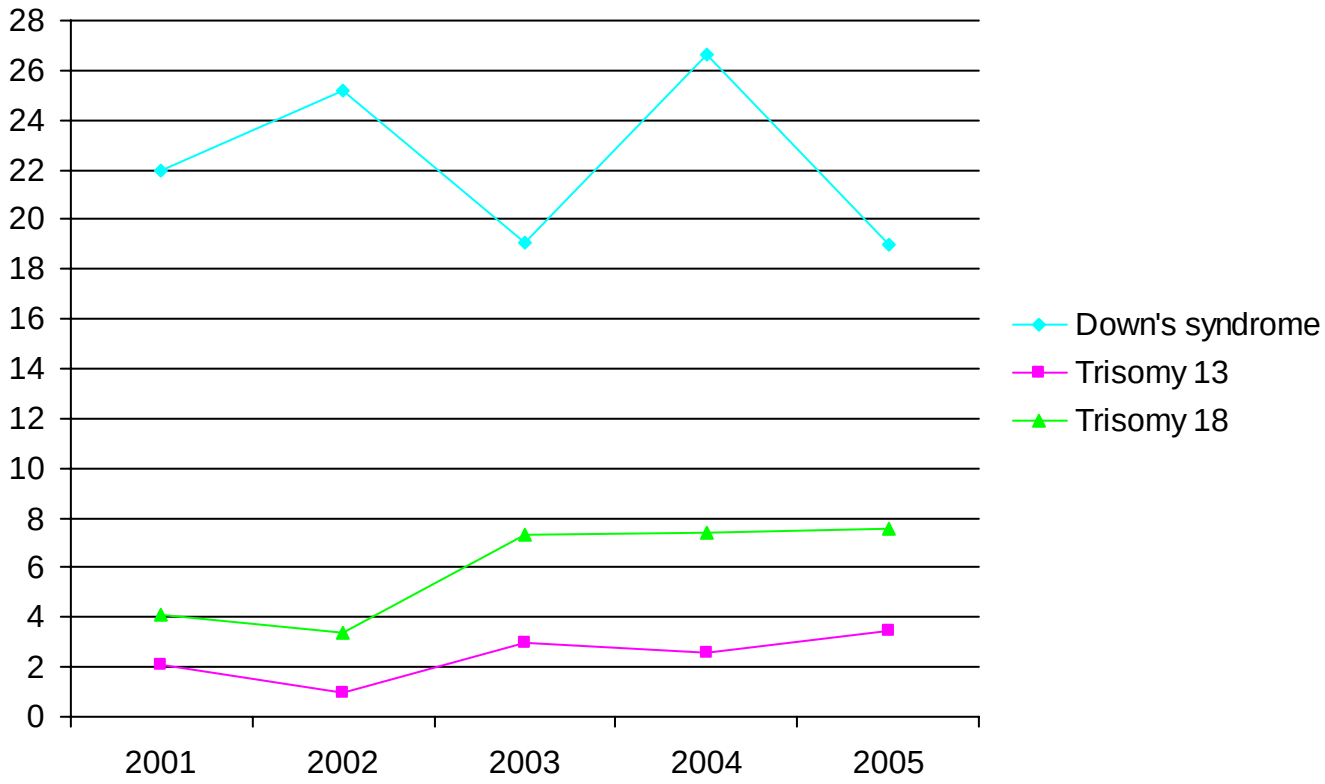
NorCAS continues to be an active member of the British Isles Network of Congenital Anomaly Registers (BINOCAR).[20] The 2007 BINOCAR AGM was held in Newcastle and hosted by the RMSO. The AGM discussed a number of issues including the funding of congenital anomaly registers, coding congenital anomalies, data validation, as well as collaborative research projects.

Figure 9.1: Total prevalence of neural tube defects, 2001-05.



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

Figure 9.2: Total prevalence of trisomies 13,18 and 21, 2001-05.



Routine Surveillance

We continue to undertake regular surveillance using control charts as well as responding to potential alerts detected by the EUROCAT surveillance procedures and those sent to the Directors of Public Health by the ONS. A further apparent cluster of gastroschisis was identified in 2006 but the resulting investigation found the cluster to have occurred due to the inclusion of cases that were incorrectly coded as gastroschisis.

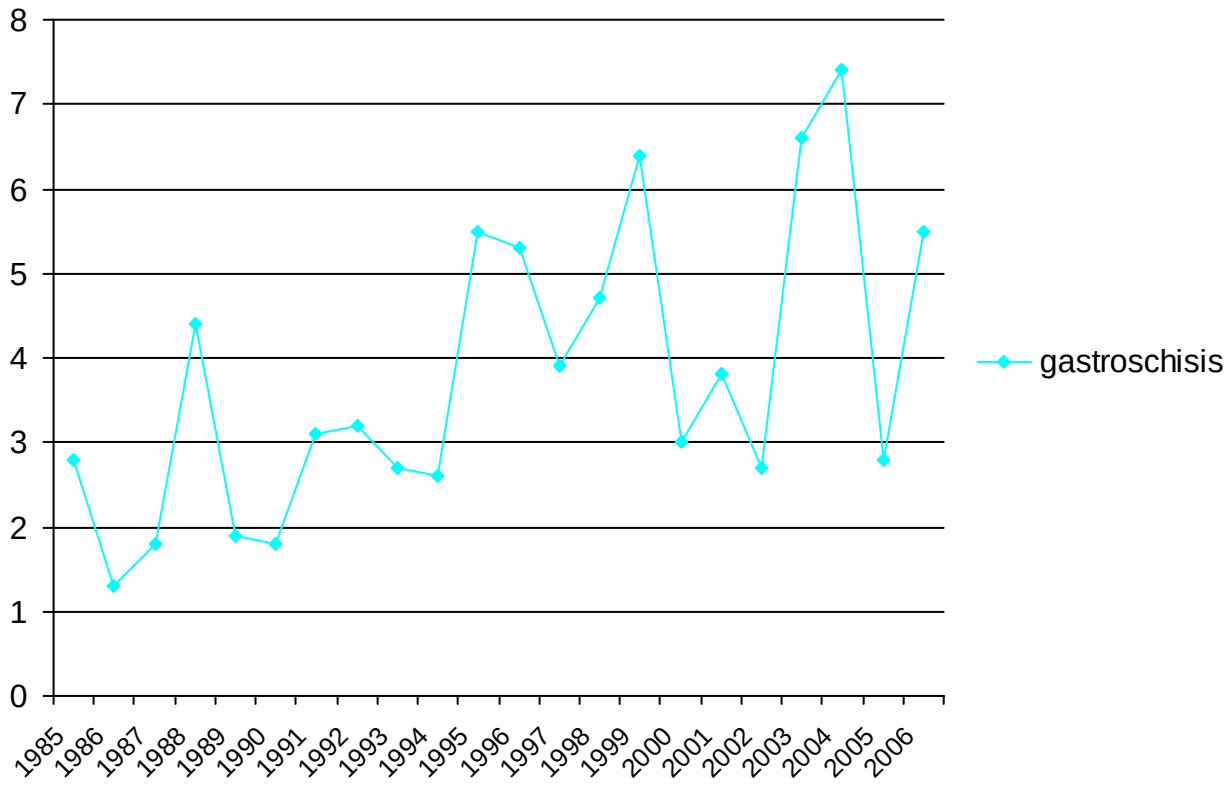
Down's Syndrome Screening Programme Audit

We continue to feedback to the regional antenatal screening co-ordinator and to individual units. We also provide information on Down's syndrome, trisomies 18 and 13 cases to the National Down's Syndrome Cytogenetic Register.

Gastroschisis

An increase in the prevalence of gastroschisis has been observed regionally, nationally and internationally. Figure 9.3 shows the year on year fluctuation in prevalence of gastroschisis in the Northern Region. The total prevalence rate of gastroschisis increased from 2.9 per 10,000 births in 2005 to 5.5 per 10,000 births in 2006. Continued monitoring of the prevalence of gastroschisis is necessary to know whether this increase continues or not.

Figure 9.3: Secular change in total prevalence of gastroschisis in the Northern Region, 1985-2006.



Research

We briefly feature the results from a recently completed research project using data held by the NorCAS.

Sacrococcygeal Teratoma: A 22 year population based study

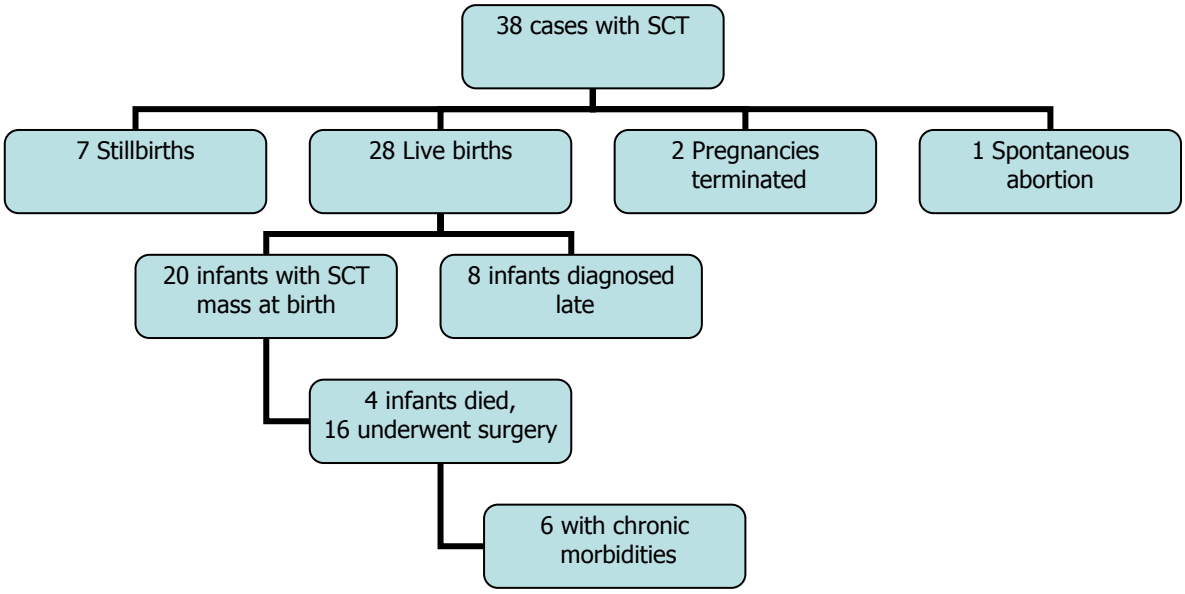
Sacrococcygeal teratomas (SCT) are a rare subset of germ cell tumours occurring predominantly in infants and children which can lead to multiple complications including malignancy and potentially death. The precise aetiology of SCT is not known but the live birth prevalence is thought to be around 1 per 35,000 to 1 per 40,000 live births. Females are thought to be affected more than males but malignancies are thought to be more frequent in males. Although there are various studies determining the incidence of SCT, this has not been clearly defined. Most of these studies are usually small case series and often tertiary centre based, and are therefore inherently biased. The aim of this study was to determine the prevalence, antenatal detection rate and outcome of SCT in a population based cohort in the Northern region of England.

Cases were identified using data for the years 1985-2006 held by the NorCAS. Antenatal diagnosis was ascertained from the notes and cross validated using the Fetal Medicine database at the RVI. Details of surgical management and histopathological reports were noted from the case notes. The incidence of malignant transformation was then analysed after cross linking with the children's cancer register and the number of deaths were

identified from the Northern Perinatal Mortality Survey. The study had approval from the regional ethics committee.

A total of 38 cases with SCT were identified and there were 754,172 live births and 4,203 stillbirths during the study period. Twenty eight infants (74%) were live born, seven babies (18%) were stillborn at or after 24 weeks gestation, two (5%) pregnancies were terminated in view of SCT and one (3%) pregnancy ended in spontaneous abortion before 20 weeks. This gives a total prevalence of 0.5 per 10,000 total births and a live birth prevalence of 0.4 per 10,000 live births. Of the 28 live born infants, 23 (82%) were females and five (18%) were males.

Figure 9.2: Flow diagram of outcome of pregnancy affected by SCT



Nineteen (50%) of these infants were diagnosed antenatally on ultrasonography. Of the 28 live born infants, 20 infants were born with SCT mass which was clinically noted at birth. The remaining eight infants were diagnosed beyond the neonatal period.

Four infants died within an hour of birth due significant haemorrhage. The remaining 16 infants underwent tumour resection within the first few days of life and all survived beyond one year of age. Six (25%) cases were noted to have chronic morbidities. Eight children who were detected at a later stage needed chemotherapy and/or surgery.

The prevalence of sacrococcygeal teratoma in the Northern region is higher than previous reports. Females were more affected as compared to males which is consistent with previous reports (4:1).[21] Infants who were live born and survived definitive surgical management seemed to have a good prognosis. This information is useful when counseling parents antenatally.

[21] Winderl LM, Silverman RK. Prenatal identification of a completely cystic internal sacrococcygeal teratoma (type IV). *Ultrasound in Obstetrics & Gynecology* 1997; 9: 425–28.

Ongoing projects

Maternal obesity and congenital anomaly risk

There is a small but accumulating body of evidence from outside the UK suggesting that maternal obesity is associated with increasing prevalence of congenital anomalies. This retrospective cohort study involves data on all women who booked in one of five maternity units in the Northern region during 2003-05, and data from NorCAS. The relationship between maternal obesity at booking and the prevalence of congenital anomalies (total and birth prevalence) is being investigated, allowing for relevant covariates including maternal age, smoking, socio-economic status, and folic acid use.

Ambient air pollution and cardiovascular system anomalies

Recent evidence suggests that air pollution adversely affects fetal and infant health. Two recent US studies were the first to suggest associations between maternal exposure to air pollution and cardiovascular anomalies. There are no published UK studies. Using NorCAS data and birth data, and routinely collected air pollution data, this study will investigate whether maternal exposure to air pollutants is associated with an increased risk of cardiovascular anomalies in the Northern Region (1985-2003). This case control study will use spatio-temporal modelling incorporating monitored air pollution and information on land use, and multiple logistic regression after controlling for relevant covariates, to investigate the relationship.

Survival of children born with a congenital anomaly

Few studies have reported the survival of children born with congenital anomalies. Such information from long-term follow up studies is required both to give appropriate information to parents and health professionals when an antenatal diagnosis is confirmed, and to identify factors associated with successful outcome. The aim of the study is to describe the survival and cause of death of children born with congenital anomalies by congenital anomaly group and type; and to explore relationships between clinical characteristics (presence of additional anomalies, birth weight, gender, plurality) and survival. Using NorCAS data, and death registrations from the ONS, we are ascertaining all deaths in children born with a congenital anomaly in the Northern region during 1985-2003, to identify surviving children. The study will provide accurate and appropriate information on survival, to parents and health professionals, for a range of congenital anomaly types.

Follow up of children with congenital anomalies long-term (*FoCAL*); The feasibility of investigating the outcomes at age two years for children born with congenital diaphragmatic hernia.

The aim of the *FoCAL* programme is to develop a standard methodology for the long-term follow-up of children with structural congenital anomalies or soft-markers and to make this information widely available for counselling expectant parents. This is the first *FoCAL* project. This two year project involving all eight regional congenital anomaly registers in England and Wales, aims to develop and test the feasibility of using a standard methodology to describe the status at age two of children born with congenital diaphragmatic hernia (CDH) and to investigate the willingness of parents to be contacted again for future follow-up. The secondary aims are to describe the incidence, the perinatal outcomes, and the pattern of mortality for those with CDH who do not survive to age two.

Publications involving NorCAS data since 2004

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- Plant ND, Hornung RJ, Coulthard MG, Keir MJ, Matthews JNS, Robson SC. Does antenatal pelvic dilation predict renal scarring? *Archives of Disease in Childhood Fetal & Neonatal Edition* 2005; 90: F339-40.

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- Draper E, Rankin J, Tonks A, Abrams KR, Field D, Clarke M, Kurinczuk JJ. Recreational drug use - a major risk factor for gastroschisis? *American Journal of Epidemiology* 2007 DOI: 10.1093/aje/kwm335

- Barisic I, Tokic V, Loane M, Bianchi F, Clazolari E, Garne E, Wellesley D, Dolk H, and EUROCAT Working Group. Descriptive epidemiology of Cornelia de Lange syndrome in Europe. *American Journal of Medical Genetics Part A* 2008; 146: 51-9.

10. NORTH OF ENGLAND COLLABORATIVE CEREBRAL PALSY SURVEY (NECCPS)

Background

Cerebral palsy is the commonest cause of long-term motor impairment in children. NECCPS began in 1993 as a prospective cerebral palsy survey across all districts in the former Northern Region. Before this, a smaller survey had operated in the Tyneside area from 1960 births.

NECCPS is a collaboration between paediatricians across the region (each district has a convenor) who use the survey for service planning, audit and research. NECCPS is based at the RMSO, under the auspices of the NEPHO.

The survey holds data on 780 children born between 1960 and 1990 in the Northumberland, Newcastle and North Tyneside districts. As of September 2007, data on a further 1214 children from the former Northern Region are held for 1991 births onwards. The data held on each child include type of cerebral palsy, birth weight, gestation, current and birth postcodes. Consent is sought from parents to include children on the Survey. Uniquely, data are held from the Lifestyle Assessment Questionnaire – an instrument specifically designed for children with cerebral palsy to measure the impact of impairment on the child and family.

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.

Links with UK and European Cerebral Palsy Registers

NECCPS collaborates with the other UK cerebral palsy registers in Oxford, Belfast, Liverpool and Edinburgh. Studies are underway or completed on trends, life expectancy and socio-economic variations in cerebral palsy.

NECCPS also collaborates with a further 11 non-UK European registers. This collaboration, funded by the European Commission, is co-ordinated by Dr Cans in Grenoble; and Dr Allan Colver from NECCPS sits on its executive committee.

Figure 10.1 shows that rates of cerebral palsy across Europe are falling in the birth-weight group 1000-1499 grams.[22]

[22] Platt MJ, Cans C, Johnson A, et al. Trends in cerebral palsy among infants of very low birthweight (<1500 g) or born prematurely (<32 weeks) in 16 European centres: a database study. *Lancet* 2007; 369: 43-50.

SPARCLE (Study of participation of children with cerebral palsy living in Europe)

As reported in previous annual reports, children with cerebral palsy in the North of England are part of a study called SPARCLE. This study lasted four years and results are now being published. 818 8-12 year old children with cerebral palsy in seven European countries were visited and 116 of these children were from the North of England. The study was co-ordinated from Newcastle.

We were very pleased that the first paper reporting results about Quality of Life was published in the Lancet Journal in June 2007; this gave the article and its findings much local, national and international publicity.

Quality of Life (QoL) was reported by the children themselves using the KIDSCREEN Instrument which captures a child's perception of their physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, financial resources, social acceptance and bullying.

- 39% of the children had severe intellectual impairment which meant they could not self report and their quality of life will be reported in a separate paper.
- Pain had a pervasive effect on all the domains of QoL
- Impairments were not associated with 6 KIDSCREEN domains. However reduced mobility was associated with reduced QoL on the physical wellbeing domain, moderate intellectual impairment with reduced QoL on the moods and emotions, and autonomy domains; language difficulty with reduced QoL on relationships with parents domain
- In children able to report their own quality of life, there is no overall difference between those with cerebral palsy and the general population of children of the same age. Quality of life is similar in children, whether disabled or not (Figure 10.2).

Rate of Cerebral Palsy among infants of 1000-1499g, from 9 European countries 1980- 1996 (3 yr moving average)

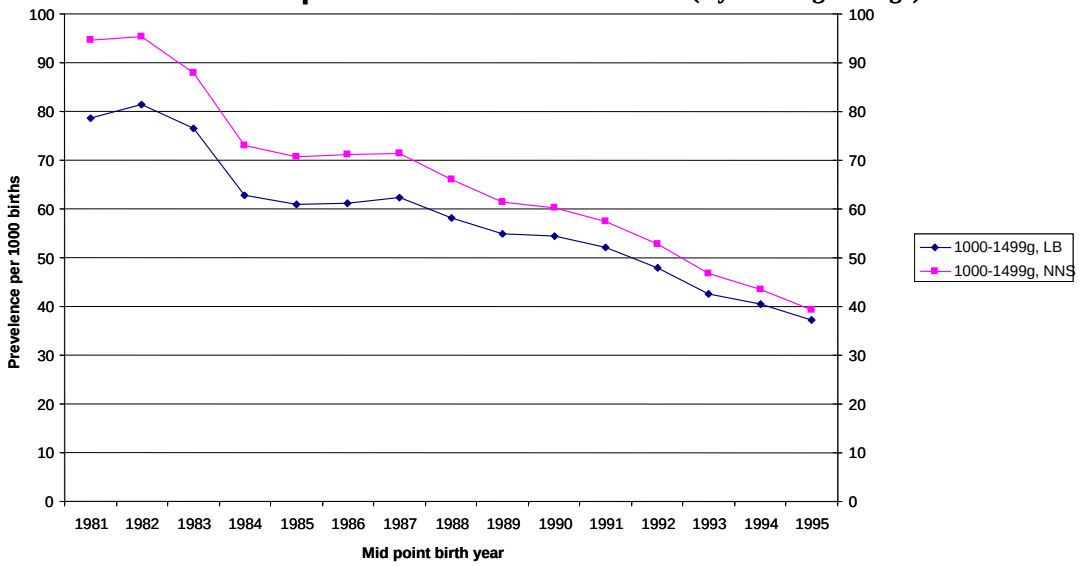
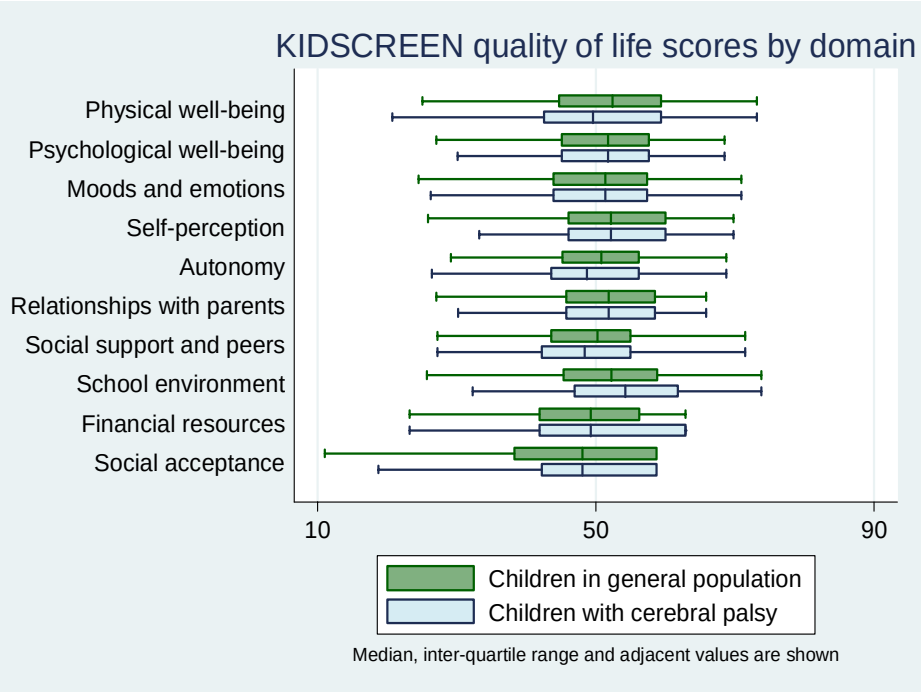


Figure 10.2: KIDSCREEN quality of life scores by domain



Further results relate to pain, mental health and participation of children with cerebral palsy; to stress experienced by parents; and to comparisons between child and parent reports of their child's quality of life.

It is very important that results are disseminated to parents, voluntary groups, public bodies and government and there is a clear plan for doing this in due course.

2007 NECCPS Annual Meeting

The theme for the twelfth NECCPS Annual meeting was Cerebral Palsy and Education and, as with recent meetings, it generated a lot of interest from parents and professionals. Over 170 people, 60 of whom were parents or carers, attended the meeting held at Trevelyan College, University of Durham. The early morning session was devoted to presentations by education professionals, parents and students with cerebral palsy in both mainstream and special schools. The rest of the day was devoted to a variety of topics besides education, including preliminary results of the SPARCLE quality of life study, which is discussed in more detail above. Talks on pain by Kathryn Parkinson and Martin Ward Platt were very well received by both parents and professionals and it is clear that this a topic that people would like to see explored in greater depth. Jenny Lingham, a parent, presented a very informative talk on parents' experiences, both good and bad, of the education system for their children with cerebral palsy. This study, based on questionnaires sent to parents of children on NECCPS of school age. Copies of presentations are available from the RMSO.

Working with Parents

When the survey started, links with parents were not well established. We have made it a priority to establish more contact with parents and families and have done so in several ways.

- Parents are sent newsletters once or twice a year, containing information on the NECCPS Annual Meeting, updates on NECCPS research and other information that NECCPS has been asked to share with parents.
- An updated 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 four years. However, all parents of children on the survey have now been contacted and given the opportunity to have their children's details removed.
- The NECCPS annual report in 2002 was designed specifically for parents and the general public.
- All parents of children on NECCPS are invited to attend the annual meeting at a reduced cost. Attendance of parents is valuable for many reasons, which include being an important forum for information sharing between parents and professionals. This is done formally during the meeting and more informally, but as importantly, during the breaks and lunch.
- Parents in most districts are contacted directly by NECCPS when they reach the age when the lifestyle assessment questionnaire is needed.
- The possibility of the provision of a moderated NECCPS website is being explored. General data are available on the RMSO website.

Current Data September 2007

The Tables show data about children whose mothers were resident in the region at birth.

Table 10.1: Number of registrations from former health "districts"

	Number of registrations of CP by year of birth											
										Incomplete		
Year	**91**	**92**	**93**	**94**	**95**	**96**	**97**	**98**	**99**	**00**	**01**	**02**
District												
Northumberland	**9**	**13**	**4**	**7**	**7**	**11**	**3**	**4**	**5**	**3**	**3**	**3**
Newcastle	9	9	13	6	5	9	9	6	2	7	4	2
North Tyneside	10	10	2	2	3	4	3	6	7	4	5	2
Newcastle & North Tyneside	**19**	**19**	**15**	**8**	**8**	**13**	**12**	**12**	**9**	**11**	**9**	**4**
Gateshead	9	8	3	5	2	6	7	2	6	7	1	4
South Tyneside	4	4	9	7	6	3	6	4	3	2	1	0
Gateshead & South Tyneside	**13**	**12**	**12**	**12**	**8**	**9**	**13**	**6**	**9**	**9**	**2**	**4**
Sunderland	**5**	**15**	**10**	**17**	**12**	**12**	**15**	**8**	**15**	**7**	**5**	**10**
North Tees	6	6	8	8	10	8	15	10	7	3	3	2
South Tees	14	12	14	7	15	14	8	8	7	8	7	2
Hartlepool	1	2	6	9	3	2	7	8	4	3	2	2
Tees	**21**	**20**	**28**	**24**	**28**	**24**	**30**	**26**	**18**	**14**	**12**	**6**
N.W. Durham	4	0	2	0	3	6	4	2	4	3	1	3
Durham	5	4	6	4	2	3	7	6	1	4	3	1
S.W. Durham	8	12	6	4	5	7	8	6	5	3	5	11
Darlington	3	3	6	4	1	5	5	1	2	2	2	6
Co. Durham	**20**	**19**	**20**	**12**	**11**	**21**	**24**	**15**	**12**	**12**	**11**	**21**
W. Cumbria	4	2	2	2	3	5	6	8	1	5	2	0
E. Cumbria	6	1	3	7	4	7	5	2	5	5	5	3
North Cumbria	**10**	**3**	**5**	**9**	**7**	**12**	**11**	**10**	**6**	**10**	**7**	**3**
North of England Excluding S. Cumbria	**97**	**101**	**94**	**89**	**81**	**102**	**108**	**81**	**74**	**66**	**49**	**51**

Table 10.2: Registration rates by former health "districts"

District or area	Three year rolling registration rate per 1000 live births						Incomplete
	1991-93	1992-94	1993-95	1994-96	1995-97	1996-98	1997-99
Northumberland	**2.43**	**2.28**	**1.75**	**2.50**	**2.15**	**1.87**	**1.27**
Newcastle	2.87	2.67	2.33	1.99	2.35	2.53	
North Tyneside	3.05	2.03	1.04	1.37	1.53	2.01	
Newcastle & North Tyneside	**2.94**	**2.42**	**1.82**	**1.75**	**2.02**	**2.32**	**2.14**
Gateshead	2.61	2.17	1.38	1.84	2.15	2.20	
South Tyneside	2.81	3.43	3.88	2.92	2.79	2.52	
Gateshead & South Tyneside	**2.70**	**2.72**	**2.48**	**2.31**	**2.43**	**2.34**	**2.40**
Sunderland	**2.50**	**3.68**	**3.59**	**3.89**	**3.80**	**3.51**	**3.94**
North Tees	2.67	3.08	3.80	3.93	5.10	5.12	
South Tees	3.22	2.72	3.08	3.19	3.40	2.84	
Hartlepool	2.31	4.49	4.77	3.86	3.44	5.18	
Tees	**2.89**	**3.13**	**3.59**	**3.53**	**3.94**	**3.94**	**3.75**
N.W. Durham	1.85	0.64	1.64	3.09	4.49	4.22	
Durham	1.65	1.60	1.44	1.11	1.48	2.00	
S.W. Durham	4.36	3.84	2.75	3.00	4.06	4.32	
Darlington	2.47	2.76	2.40	2.21	2.34	2.36	
Co. Durham	**2.55**	**2.29**	**2.01**	**2.11**	**2.72**	**2.94**	**2.56**
W. Cumbria	1.52	1.25	1.64	2.25	2.85	3.51	
E. Cumbria	1.53	1.69	2.14	2.91	2.89	2.84	
North Cumbria	**1.52**	**1.50**	**1.94**	**2.64**	**2.87**	**3.19**	**2.71**
North of England (excludes South Cumbria)	**2.58**	**2.60**	**2.50**	**2.65**	**2.89**	**2.95**	**2.75**

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APPENDIX 1 NUMBERS OF BIRTHS 1991-2006 IN THE NORTH EAST PLUS "NORTH CUMBRIA"

Year	Live births	Stillbirths	Total births (live births + stillbirths)
1991	39 051	208	39 259
1992	37 795	216	38 011
1993	36 509	224	36 733
1994	35 026	219	35 245
1995	34 102	231	34 333
1996	33 666	202	33 868
1997	32 874	187	33 061
1998	32 008	195	32 203
1999	30 938	171	31 109
2000	29 624	161	29 785
2001	28 906	153	29 059
2002	29 208	183	29 391
2003	30 158	171	30 329
2004	31 018	184	31 202
2005	31 429	182	31 611
2006	32 491	169	32 660

Note the live birth data is obtained from ONS. Totals vary slightly (average 10 per year in 30 000 births) from ONS published live births for the North East and North Cumbria due to changes in post code assignment and ward boundaries. Stillbirths are as reported to the RMSO.

APPENDIX 2 PROGRAMMES FOR ANNUAL MEETINGS 2007

- North of England Collaborative Cerebral Palsy Survey Annual Meeting 21 March 2007
- Multiple Pregnancy Register 21 May 2007
- Northern Diabetes in Pregnancy Survey Summer Workshop 3 July 2007
- Perinatal Mortality and Morbidity Survey Annual Meeting 12 October 2007
- Northern Congenital Abnormality Survey Annual Meeting 14 November 2007

Twelfth Conference and Annual Meeting of the THE NORTH OF ENGLAND COLLABORATIVE CEREBRAL PALSY SURVEY 21 March 2007 10am-4pm Trevelyan College, University of Durham

Cerebral Palsy & Education

Morning session

9.30 Coffee and registration

10.00 Chair: Dr Sethu Wariyar

10.05 What is Conductive Education? How is it implemented in school? Anne Coates & Katie Murray, Percy Hedley School

10.30 Visiting the Peto Institute in Budapest, Hungary. Carol Bucknall & Jill Anderson

10.45 What is it like being in mainstream school? Jordan Raiye, Year 9 Student, Oxclose School and Pupils from Venerable Bede School, Sunderland

11.00 What is it like being in special school? Pupils from Percy Hedley school

11.15 **Coffee**

11.45 Update of study of adolescents with cerebral palsy. Catherine Tuffrey, Teaching and Research Fellow, Northumbria Healthcare NHS Trust

11.55 How does studying congenital anomalies help us understand cerebral palsy? Judith Rankin, Principal Research Associate, Newcastle University

12.15 How does quality of life of children with cerebral palsy compare with that of other children? Allan Colver, Professor of Community Child Health, Newcastle University

12.50 Lunch

Afternoon session

13.50 Chair: Dr Peter Morrell

13.50 How 'inclusion' is operationalised in early years settings. Findings from a research study undertaken in Newcastle and Sheffield. Emma Clavering. Research Associate, Newcastle University, Janice McLaughlin, Senior Lecturer, Newcastle University

14.20 Parents' experiences of having children with cerebral palsy in mainstream or special education. Jenny Lingham

14.35 Where do children with cerebral palsy in the north east attend school? NECCPS data Alison Guadagno, SpR in Paediatric Neurodisability & Helen Leonard, Paediatrician

14.50 Pain in children. Martin Ward Platt, Consultant Paediatrician, Royal Victoria Infirmary
Pain in children with cerebral palsy. Kathryn Parkinson, Senior Research Associate, Newcastle University

15.45 Further discussion and close

R M S O

REGIONAL MATERNITY SURVEY OFFICE

Northern Multiple Pregnancy Register
Inaugural Spring Workshop

Multiple pregnancy: improving outcomes, managing risks

Monday 21 May 2007, 12.00-17.00
Education Centre, Queen Elizabeth Hospital, Gateshead

12.15	**Lunch (registration from 12.00)**	
13.00	Welcome and outline of the afternoon	Chair: Chris Wright
13.15	*Keynote speaker*: Care for couples with multiple pregnancy: A vision for the future	Jane Denton Director, Multiple births foundation
14.00	Optimal mode of delivery in twins	Andrew Loughney
14.20	The benefits of a specialist multiple pregnancy antenatal clinic	Sandra Bosman
14.40	**Tea**	
	The Northern Multiple Pregnancy Register	Chair: Tricia Cresswell
15.00	How are we doing? – multiple pregnancy in the Northern region	Judith Rankin
15.20	Consent and reporting – current issues	Ruth Bell
15.40	Infant mortality in twins and singletons born before 30 weeks	Brajagopal Ray
16.00	The way forward – improving outcomes by developing regional standards of care	Stephen Sturgiss
16.20	Discussion	
16.45	**End**	

R M S O

REGIONAL MATERNITY SURVEY OFFICE

Northern Diabetes in Pregnancy Survey
Summer Workshop

Programme

Tuesday 3 July 2007, 12.30-17.00
Marriott Hotel, Gosforth Park, Newcastle upon Tyne

12.30	**Lunch**	
13.15	Welcome and outline of the afternoon	Dr Tricia Cresswell
13.20	Intergenerational risk of gestational diabetes	Dr David Simmonds
14.20	Launch of gestational diabetes standards	Dr Ruth Bell & Dr Rudy Bilous
14.50	**Tea**	
15.10	CEMACH report – national and local issues	Dr Jo Modder
16.10	Baseline Audit of GDM for Northumbria	Dr Nick Lewis Barned
16.30	Type 2 diabetes – review of data	Kath Bailey
17.00	**End**	

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R M S O
REGIONAL MATERNITY SURVEY OFFICE

Perinatal and Maternal Mortality Survey
Annual Meeting
Freeman Hospital, Newcastle upon Tyne, 12th October 2007

Changing practice at the margins

09.00	**Coffee and registration**	
	Chair Mr Willie Reid	
09.30	Welcome and introduction to the day	Willie Reid
09.40	CEMACH Update	Tricia Cresswell/ Marjorie Renwick
10.10	Feticide : Midwife Perspective	Ruth Graham/ Barbara Thompson
10.40	Intra-partum Events : Mortality and Morbidity Outcomes	Martin Ward Platt/ Lorna Gillepsie
11.10	**Coffee**	
11.30	Implications of the Human Tissue Act	Chris Wright
12.10	Active surveillance of perinatal mortality	Mary Bythell
12.30	**Lunch**	
	Chair Rev Bryan Vernon	
13.30	Team Obstetrics--communication between professionals	Willie Reid
14.10	Changing Practice in North Tees	Janet Alderton/ Kath Mannion
15.00	**Home Births:** Past, Present & Future	Jean Davies
15.30	Discussion	
16.00	**Close**	

R M S O
REGIONAL MATERNITY SURVEY OFFICE

NorCAS Annual Meetng 2007

Wednesday November 14th – The Education Centre, Queen Elizabeth Hospital

Chair: **Professor Steve Robson, Professor of Fetal Medicine, RVI**

09.30 Coffee and registration

10.00 Introduction to the day

10.05 Congenital sacrococcygeal teratoma: A 22 year population-based study
Dr Ravi Swamy, SpR in Paediatrics, NGH

10.20 Lung anomalies
Jai Mangalore and Braja Ray, SpRs in Paediatrics, RVI

10.35 An audit of late terminations of pregnancy
Rachel Taylor & Stefan Zalweski, Final year medical students

10.50 The relationship between cerebral palsy and congenital anomalies
Dr Judith Rankin, Reader, Newcastle University

11.05 NorCAS Data – an update
Dr Sam Richmond, Consultant Paediatrician, Sunderland Hospital, Dr Rob Bolton, Staff Grade Paediatrician, South Tyneside Hospital & Dr John Atkins, Retired Obstetrician

11.30 Coffee

12.00 National survey of feticide
Dr Ruth Graham, Lecturer in Sociology, Newcastle University

12.30 Management of obesity – putting policy into practice
Dr Helene Brandon, Consultant Obstetrician, Queen Elizabeth Hospital

12.50 Lunch

Theme: **Screening issues**
Chair: **Professor John Burn, Professor of Clinical Genetics, Institute of Human Genetics**

14.00 Cell free DNA and other non-invasive testing (title TBC)
Dr Lyn Chitty, Reader in Genetics and Fetal Medicine, Institute of Child Health, UCL

14.40 Cystic fibrosis screening – one year on
Dr David Spencer, Consultant in Respiratory Paediatrics, Dr Sri Prudon, Cystic Fibrosis Fellow FRH, Kim Moonlight, Regional Antenatal Screening Coordinator, Public Health Group NE

15.05 Atypical biochemical results
Steve Turner, Principal Biochemist, RVI, Dr Hillary Wastell, Consultant Clinical Biochemist, RVI

15.25 Performance management of screening
Dr Stephen Sturgiss, Consultant in Fetal Medicine, RVI

15.40 Panel discussion: Issues in screening
16.00 Close

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Appendix 3 RMSO staff and contact details

RMSO Staff and contact details

Dr Judith Rankin	Acting Director	j.m.rankin@ncl.ac.uk
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Dr Tricia Cresswell	Associate Director	tricia.cresswell@cdpct.nhs.uk
Marjorie Renwick	CEMACH Regional Manager	marjorie.renwick@rmso.org.uk
Mary Bythell	Data Manager: NorCAS/ Cerebral Palsy	mary.bythell@ncl.ac.uk
Danielle Crowder	Data Manager: Diabetic Survey/ NorSTAMP	danielle.crowder@ncl.ac.uk
Julie Battista	Administrative Assistant	j.h.battista@ncl.ac.uk
Shirley Burn	Administrative Assistant	shirley.burn@ncl.ac.uk

APPENDIX 4 MEMBERSHIP OF STEERING GROUPS

RMSO Steering Group/ Perinatal Mortality Survey (PMS/CEMACH) (now combined)

Dr Joan Aarvold	Programme Director, Univ Northumbria
Dr Ruth Bell	Associate Director, RMSO
Prof. Rudy Bilous	Consultant Diabetologist
Ms Mary Bythell	Data Manager, RMSO
Prof. Allan Colver	Professor of Community Child Health
Dr Tricia Cresswell	Associate Director RMSO/Director of Public Health
Mr David Evans	Consultant Obstetrician
Dr Alan Fenton	Consultant Neonatologist
Ms Kath Mannion	LSA Midwifery Officer
Mr Paul Moran	Consultant in Fetal Medicine
Dr Peter Quigley	General Practitioner
Dr Judith Rankin	Acting Director, RMSO
Mrs Marjorie Renwick	Regional CEMACH Manager
Dr Steve Sturgiss	Consultant Fetal Medicine
Dr Bryan Vernon	Lecturer in Medical Ethics/**Chair**
Prof. John Wilkinson	Director NEPHO
Dr Chris Wright	Consultant Perinatal Pathologist
Dr Jonathan Wyllie	Consultant Neonatologist

Northern Congenital Abnormality Survey (NorCAS) (current)

Mr John Atkins	Retired Consultant Obstetrician
Dr Rob Bolton	Staff Grade Paediatrician
Prof John Burn	Professor of Clinical Genetics
Ms Mary Bythell	Data Manager, RMSO
Mrs Gill Eglington	Antenatal Screening Co-ordinator
Dr Carole English	Cytogeneticist
Mr Bruce Jaffray	Consultant Paediatric Surgeon
Dr Heather Lambert	Consultant Paediatric Nephrologist
Dr Ann Lawson	Consultant Paediatric Surgeon
Dr Iona Macleod	Consultant Obstetrician
Dr Philippa Marsden	Consultant Obstetrician
Ms Kim Moonlight	Regional Antenatal Screening Coordinator
Prof. Tanja Pless-Mulloli	Professor of Environmental Epidemiology
Dr Judith Rankin	Acting Director, RMSO
Dr Sam Richmond	Consultant Paediatrician
Prof Steve Robson	Consultant in Fetal Medicine
Mr John Scott	Retired Consultant Paediatric Surgeon
Dr Miranda Splitt	Consultant Clinical Geneticist
Dr Steve Sturgiss	Consultant in Fetal Medicine
Dr Simon Thomas	Reader in Therapeutics
Dr Martin Ward Platt	Clinical Director RMSO/Consultant Neonatologist
Prof John Wilkinson	Director NEPHO/**Chair**
Dr John Wolstenholme	Cytogeneticist
Dr Chris Wren	Consultant Paediatric Cardiologist
Dr Chris Wright	Consultant Perinatal Pathologist

Northern Survey of Twins and Multiple Pregnancies (current)

Dr Ruth Bell	Associate Director, RMSO
Dr Steve Bober	Consultant Obstetrician
Ms Sandra Bosman	Midwife
Dr Helene Brandon	Consultant Obstetrician
Dr Helen Cameron	Consultant Obstetrician
Dr Nick Embleton	Consultant Neonatologist
Dr Jaime Forsey	Consultant Obstetrician
Dr Svetlana Glinanaia	Senior Research Associate
Dr Phillipa Marsden	Consultant Obstetrician
Dr Jane Milne	Consultant Obstetrician
Dr Jerry Oghoetuoma	Consultant Obstetrician
Dr Judith Rankin	Acting Director, RMSO
Mrs Marjorie Renwick	Operational Manager, RMSO
Dr Martin Ward Platt	Clinical Director, RMSO
Dr Helen Simpson	Consultant Obstetrician
Dr Steve Sturgiss	Consultant Fetal Medicine/ **Chair**
Dr Ravi Swarmy	SpR, Neonatology
Dr Chris Wright	Consultant Neonatal Pathologist

Northern Diabetic Pregnancy Survey (current)

Mrs Kath Bailey	Assistant Director (Technical), NEPHO
Dr Ruth Bell	Associate Director, RMSO
Mrs Mary Bilous	Diabetic Specialist Nurse
Prof. Rudy Bilous	Consultant Diabetologist/ **Chair**
Dr Helene Brandon	Consultant Obstetrician
Prof John Davison	Consultant Obstetrician
Dr Gillian Hawthorne	Consultant Diabetologist
Mr Stuart Hutchison	Consultant Obstetrician
Ms Shirley Johnson	Midwife
Dr Bill Lamb	Consultant Paediatrician
Dr Nick Lewis-Barnard	Consultant Physician
Ms Andrea Miller	Midwife
Ms Shirley Pearson	Diabetic Specialist Nurse
Mrs Marjorie Renwick	Operational Manager, RMSO
Dr Jason Waugh	Consultant Obstetrician
Mr Rob Wood	Consultant Obstetrician

North of England Collaborative Cerebral Palsy Survey (current)

Dr Kailash Agrawal	Consultant Paediatrician
Dr Nigel Brewster	Consultant Paediatrician
Ms Mary Bythell	RMSO Data Manager
Dr Allan Colver	Professor of Community Child Health/ **Chair**
Dr Nnenna Cookey	Consultant Paediatrician
Dr Mary Gibson	Consultant Paediatrician
Dr Karen Horridge	Consultant Paediatrician
Dr Christine Jessen	Consultant Paediatrician
Dr Angela Johnston	Consultant Paediatrician
Dr Beena Kurup	Consultant Paediatrician

Dr Eileen Lee	Consultant Paediatrician
Dr Rosemary Menzies	Consultant Paediatrician
Dr Surendra Pandey	Consultant Paediatrician
Dr Sheila Precious	Consultant Paediatrician
Ms Brenda Spilsbury	Children's Physiotherapist
Dr Ria Willoughby	Consultant Paediatrician
Ms Virginia Wood	Children's Physiotherapist

APPENDIX 5 PUBLICATIONS INVOLVING RMSO DATA

(excluding NECCPS – see page 64)

1. Bythell M, Bell R, Taylor R, Zalweski S, Wright C, Rankin J, Ward Platt M. The contribution of late termination of pregnancy to stillbirth rates in Northern England, 1994-2005. *BJOG: An International Journal of Obstetrics & Gynaecology* 2008 (in press)
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