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NORTH EAST PUBLIC HEALTH OBSERVATORY

R M S O
REGIONAL MATERNITY SURVEY OFFICE

Northern Regional Maternity Survey Office Annual Report 2005

including final data for 2004 and provisional data for 2005

December 2006

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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 2005 were again higher (31,611) than in 2004 (31,202) and 2003 (30,329).

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 2005, 127 were unexplained antepartum stillbirths (chapter 2).

4. The most important cause of infant mortality is malformation (congenital anomaly) followed by immaturity, Sudden Infant Death Syndrome (SIDS) and infection (chapter 2).

5. A set of regional principles has been agreed for the investigation of Sudden Unexpected Death in Infancy (SUDI) (chapter 2 and Appendix 5).

6. The contribution of SIDS to neonatal, postneonatal and infant deaths is similar in 2005 to that recorded in 1999 (chapter 2).

7. A detailed exploration of regional trends in stillbirth over the last two decades demonstrated (chapter 3):
   - Stillbirth rates (28 or more weeks) declined by about one third during the 1980s and 1990s.
   - The improvement in stillbirth rates was mainly a result of reductions in stillbirth due to congenital anomaly, pre-eclampsia, antepartum haemorrhage and intrapartum related deaths.
   - There was a greater improvement in stillbirth rates in multiple births and in low birthweight categories than for lower risk categories.
   - There were adverse changes in the population risk profile, with increasing proportions of older mothers, multiple births, and low birthweight babies.
   - These adverse changes had only a small impact on population stillbirth rates because of the marked improvements in stillbirth rates in high risk categories.
   - The main challenge to further decline in stillbirths is the continuing high rate of unexplained antepartum stillbirth at term, in women with no apparent risk factors or complications.

8. Post-mortem rates across the region remain at disappointingly low levels (chapter 4). Even for antepartum stillbirth the rate in 2005 was only 55%.

9. 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 5).

10. Building on the success of the Northern Diabetic Pregnancy Survey (NDPS), consensus standards on the care of mothers and their babies in pregnancies complicated by gestational diabetes are being developed (chapter 6)

11. 2005 delivery statistics by unit are remarkably similar to those for 2004 (Chapter 7). Considerable variation remains between similar size units.

12. A recent scoping study of data on maternal obesity has shown that data collection systems vary across the region, and that health care professionals voiced consistent concerns relating to maternal obesity. (Chapter 8)

13. The twinning rate for 2005 (14.9 per 1,000 maternities) is slightly higher than that reported for 2004 and remains higher than that recorded for the years 1998 - 2001 (Chapter 9).

14. The contribution of maternal lifestyle choices (diet, smoking, alcohol consumption, drug use) and assisted conception to congenital anomaly risk require further investigation (Chapter 10).

15. SPARCLE (study of participation of children with cerebral palsy living in Europe) has been ongoing for four years and is nearly completed. Eight hundred and eighteen 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. Some preliminary findings are highlighted in chapter 11.

SUMMARY MORTALITY RATES

North East Region and "Northern Region" 2004 (final), 2005 (provisional): Summary of perinatal and infant mortality data (RMSO) and number of births (ONS).
2004 and 2005 data for England & Wales (ONS)

	NORTH EAST REGION		NORTHERN REGION		ENGLAND & WALES	
	2004	2005	2004	2005	2004	2005
BIRTHS						
Total	27972	28411	31202	31611	643253	649318
Live	27803	28247	31018	31429	639721	645835
STILLBIRTHS						
Number	169	164	184	182	3532	3483
Rate (/1000 total births)	6.0	5.8	5.9	5.8	5.5	5.4
PERINATAL DEATHS						
Number	224	228	245	257	5254	5174
Rate (/1000 total births)	8.0	8.0	7.9	8.1	8.2	8.0
EARLY NEONATAL DEATHS						
Number	55	64	61	75	1722	1691
Rate (/1000 live births)	2.0	2.3	2.0	2.4	2.7	3.4
LATE NEONATAL DEATHS						
Number	22	26	24	27	517	529
Rate (/1000 live births)	0.8	0.9	0.8	0.8	0.8	0.8
POST-NEONATAL DEATHS						
Number	45	51	54	56	1033	1028
Rate (/1000 live births)	1.6	1.8	1.7	1.8	1.6	1.6
INFANT DEATHS						
Number	122	141	139	158	3272	3248
Rate (/1000 live births)	4.4	5.0	4.5	5.0	5.1	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 2005 by the Northumberland, Tyne and Wear Strategic Health Authority and the County Durham and Tees Valley Strategic Health Authority plus "North Cumbria" (Carlisle and District PCT, West Cumbria PCT and Eden Valley PCT). Data are still presented to this boundary for historical continuity.

CONTENTS

1. INTRODUCTION

This report

This is the twenty-fourth annual report produced by the Regional Maternity Survey Office (RMSO). The reports have changed in format over the years but the aims of the report remain the same:

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

Each chapter provides an update on one of the surveys and how data 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 Regional Maternity Survey Office (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.

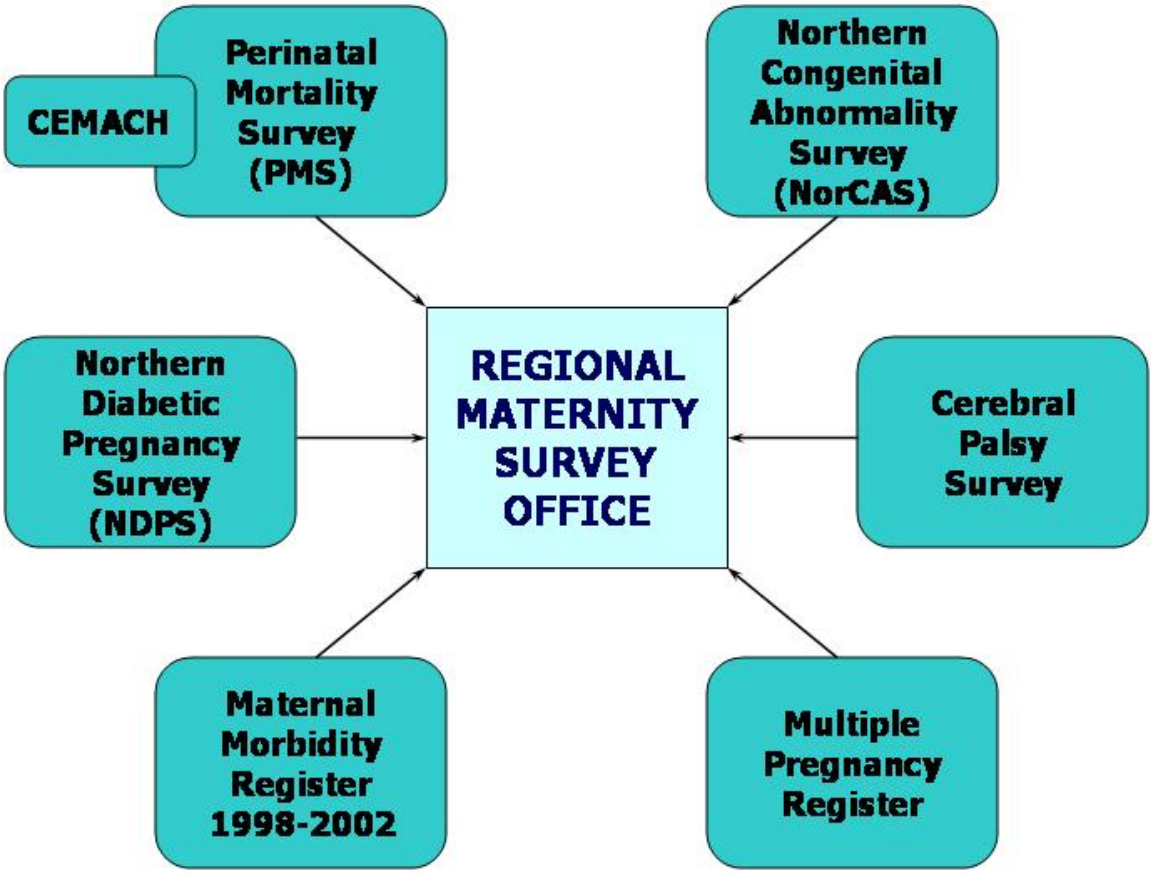
In recognition of the importance of studying morbidity, the RMSO has also hosted a Multiple Pregnancy Register since 1998. The Regional Diabetic Pregnancy Survey (established in 1994) was incorporated into the RMSO during 1999. In addition the RMSO has hosted the North of England Collaborative Cerebral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

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

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

The NorCAS Annual Meeting in October 2005 celebrated 20 years of the NorCAS and 25 years of the PMS were celebrated at the Annual Meeting in March 2006.

Figure 1.1: The Surveys and Registers

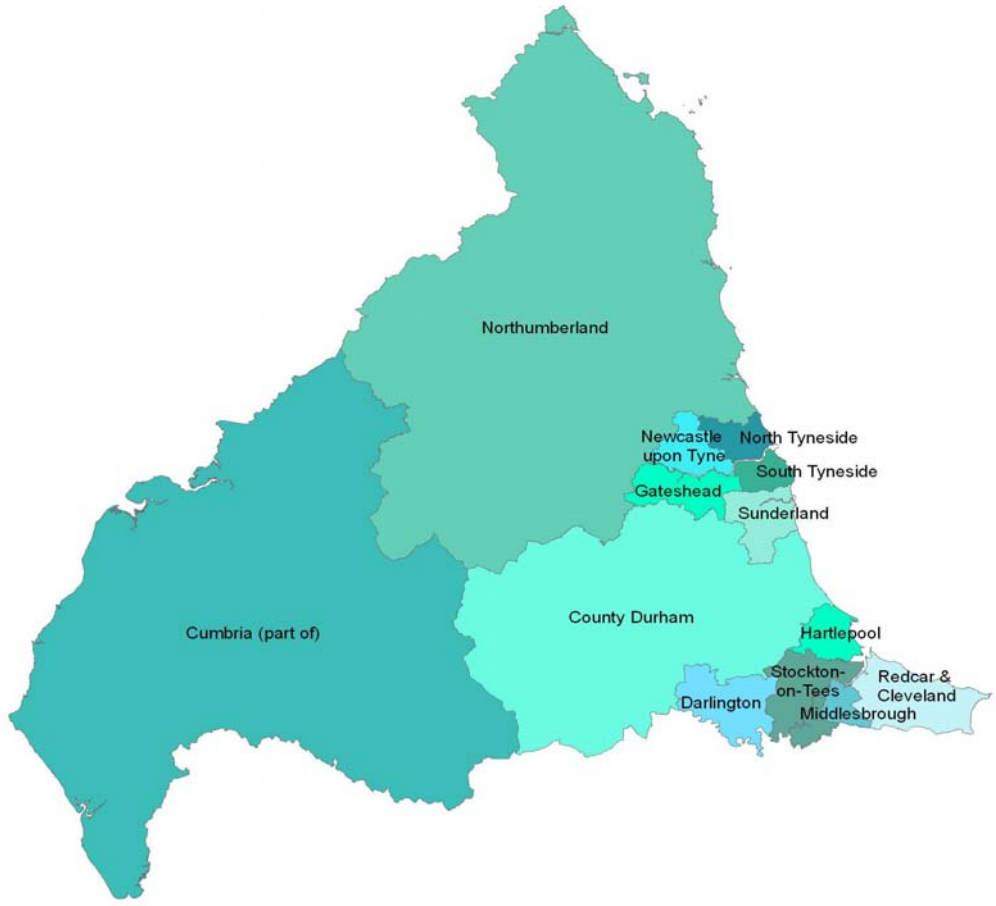


Boundaries for data collection and reporting

This is the fourth 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 this year 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. This year totals are also presented for the North East region.

Map 1.1: Unitary and district authorities covered by the RMSO



Northumberland County comprises the districts of Alnwick, Berwick, Blyth Valley, Castle Morpeth, and Tynedale. Durham County comprises 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 (see Appendix 1 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. 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 is included in Appendix 2.

RMSO funding

The RMSO currently has three main sources of funding:

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

Additional funding continues to be sought. It is important that the RMSO is acknowledged in all publications and presentations, and that, where the paper has involved NorCAS data, the Department of Health is also acknowledged.

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 Diabetic Pregnancy Survey (see Appendix 3 for programmes). These meetings are used to present work which has utilized the data and to debate controversial and topical issues. Issues from the meetings are highlighted in some of the chapters.

2. PERINATAL MORTALITY SURVEY (PMS)

Celebrating 25 years of the survey

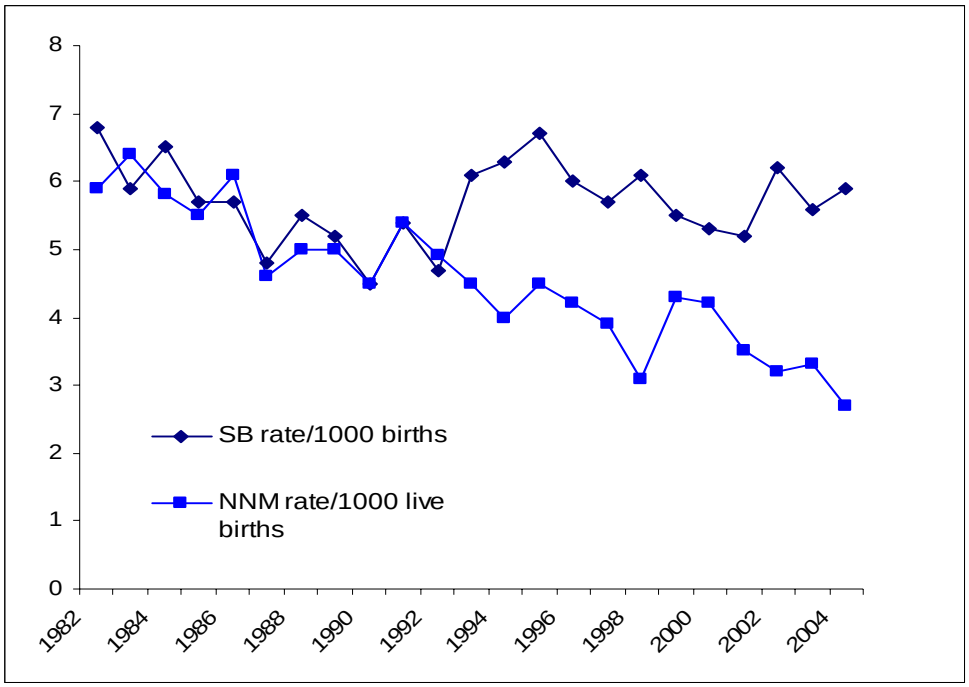
The annual meeting in March 2006 started with a session entitled **"1981 to 2006, problems then and now".** The contributors to this session were:

- Dr Edmund Hey who started the PMS and led the RMSO through the 1980s;
- Mr John Davison who has been and continues to be a key supporter of the RMSO throughout the 25 years;
- Dr Chris Wright who was Clinical Director of the RMSO in the 1990s and continues to be a major contributor to the work of the RMSO.

Their presentations highlighted trends, changes in practice and ongoing challenges in relation to reducing mortality and morbidity.

One of the key issues raised was the lack of progress in reducing stillbirths (figure 2.1). This is analysed in detail in chapter 3.

Figure 2.1: Trends in stillbirth (SB) rate and neonatal mortality (NNM) rate 1982-2004

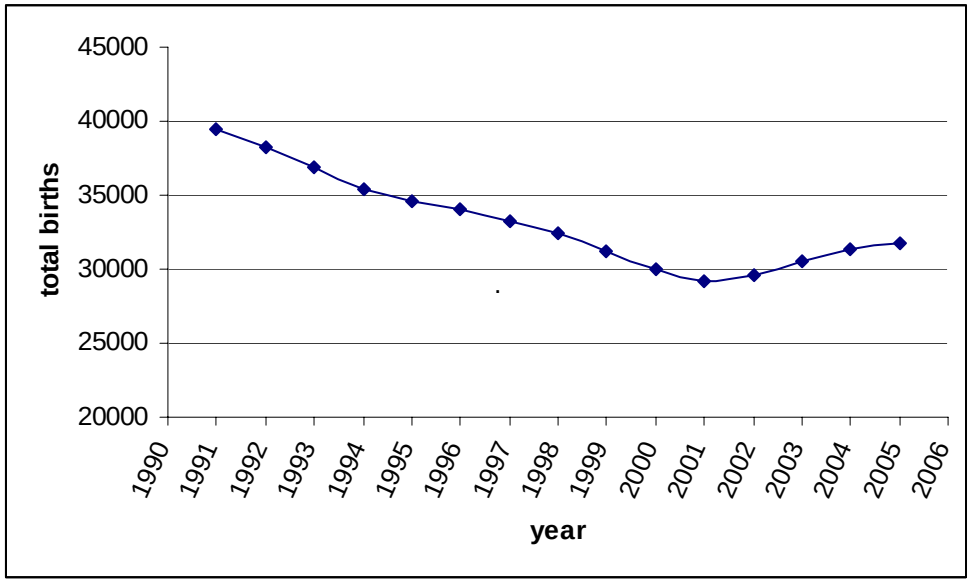


Note change in stillbirth definition in 1992.

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 2005 were again higher (31,611) than in 2004 (31,202) and 2003 (30,329) as shown in Figure 2.2.

Figure 2.2: Total Births 1991-2005 in the North East plus "North Cumbria"



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 (see Appendix 4).

Perinatal deaths and mortality rates

Table 2.1 gives the numbers of registered births (ONS data), perinatal deaths (RMSO data) and perinatal mortality rates in each Local Authority (district and unitary) for the last three years. Some districts show considerable year-to-year variation in perinatal mortality, which to a large extent reflects the relatively small number of deaths involved. In an attempt to overcome this, average perinatal mortality rates for the three year periods 2002-2005 and 2003-2005 are provided.

At least some of the variation in perinatal mortality between districts and over time may lie in the numbers of infants with gestations less than 24 weeks judged to have died in the neonatal period (and therefore contributing to perinatal mortality) rather than in utero (classified as a spontaneous abortion). For this reason the WHO and others have recommended that infants less than 500g should be excluded from perinatal mortality statistics. Table 2.2 shows the numbers of perinatal deaths of infants weighing at least 500g; those weighing at least 1kg; those weighing at least 1kg who were also normally-formed; and appropriate perinatal mortality rates for 2004 and 2005 and for 2002-2005. Excluding very low birthweight babies largely removes the contribution of extreme prematurity to perinatal mortality and allows an assessment of the residual mortality for larger infants.

Unit data

Table 2.3 gives timing of death and perinatal mortality rate by hospital maternity unit of delivery. In general terms, district to district comparisons reflect socioeconomic and other population factors and, to a lesser extent, the health care factors (access and quality)

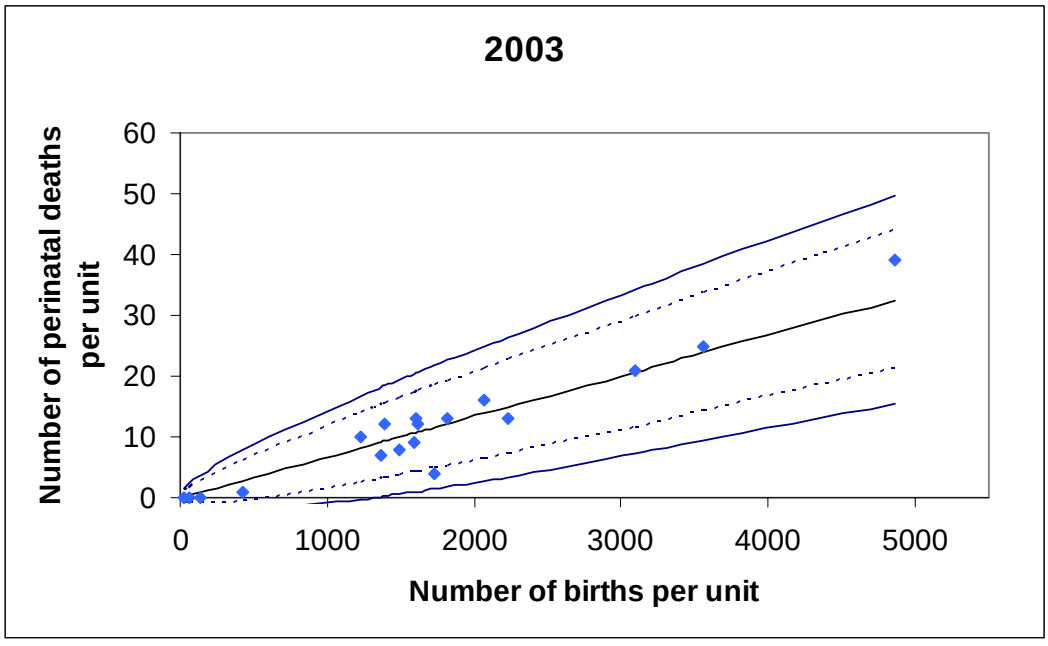
resulting in the measured outcome which here is mortality. While unit to unit comparison may allow a closer focus on health care factors, it continues to reflect the underlying population factors. It is inadvisable to come to firm conclusions using annual perinatal mortality rates based on relatively 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 objective is to regularly monitor perinatal deaths by unit to flag up unusually high rates as soon as possible and to alert units of potential problems 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. Annual perinatal mortality data for the region's maternity units in 2003 are shown in figure 2.3. Each data point represents a maternity unit, the centreline the expected number of perinatal deaths, the dotted lines two standard deviation warning limits and the solid blue lines three standard deviation control limits. The two sets of control limits represent 95% and 99.9% confidence limits, respectively. All units fall within the control limits. To ensure that monitoring is clinically meaningful, all stillbirths due to feticide have been removed from the analysis and only those cases booked and delivered at a unit are included.

Figure 2.3: Perinatal deaths by unit, 2003



As published in last year's report, one unit showed an unusually high perinatal mortality rate for 2004. This is seen graphically in Figure 2.4, where Unit A lies above the 99.9% confidence limits. This unit was made aware of the raised rate and a thorough clinical investigation was carried out. The rates for 2005 are back within normal rates for all hospitals, as seen in Figure 2.5.

Figure 2.4: Perinatal deaths by unit, 2004. Note that one unit falls outside of the control limits

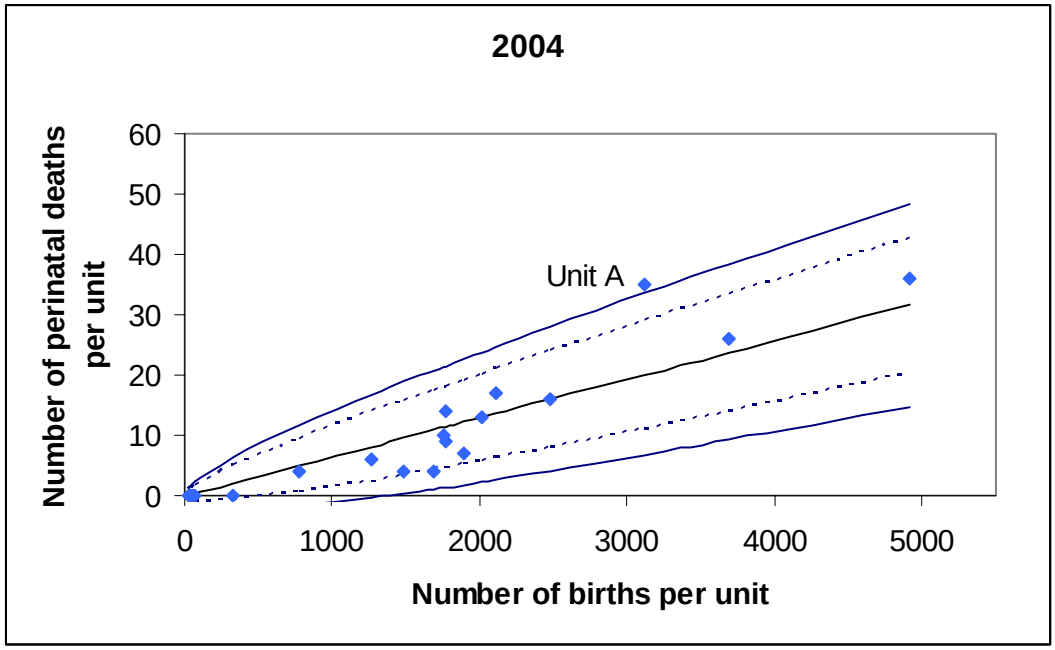
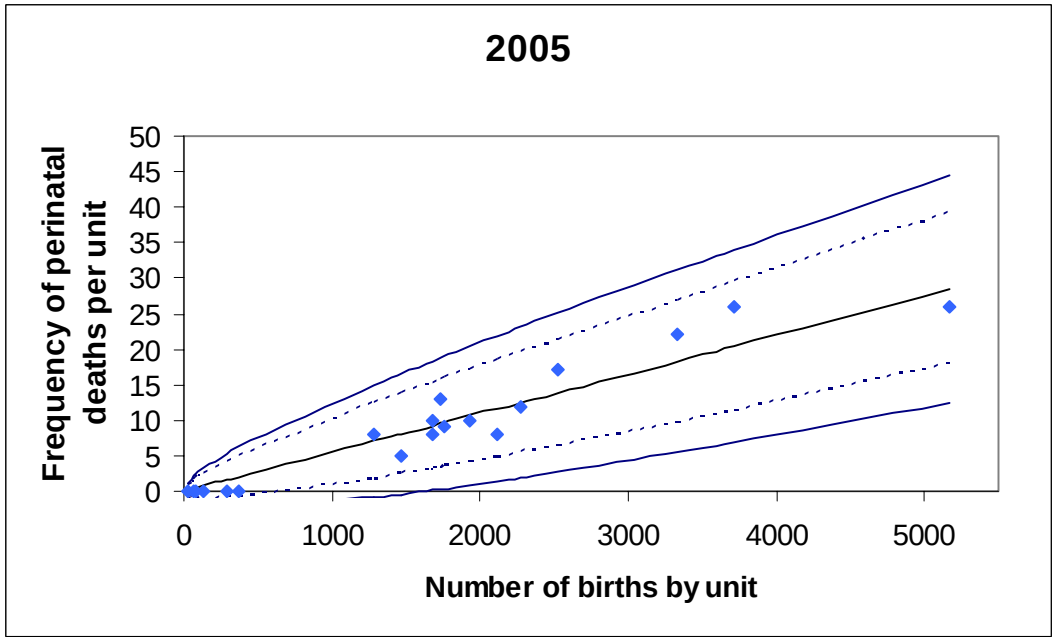


Figure 2.5: Perinatal deaths by unit, 2005. All units fall within the control limits



The numbers of births by unit are not available until well into the following year. Therefore, the 2004 deaths were plotted against 2003 births and the 2005 deaths against 2004 births and the overall outcomes were the same as when plotted against the actual number of births for the appropriate year. Unless the numbers of births change by a large amount, the previous year's births are a valid proxy for the current year's births.

To increase the timeliness of the monitoring, quarterly monitoring will be carried out, one quarter in arrears, plotted against the previous year's births. This was done in June 2006 for

the perinatal deaths delivered during the first quarter of 2006 and one unit was found to be on the upper control limit. The unit has been notified. In future, any unit exceeding the 95% warning limit will be contacted.

Infant mortality

The total numbers of late abortions (20-23 weeks gestation), stillbirths, neonatal and post neonatal deaths for each local authority during 2003 and 2004 are presented in table 2.4, together with the calculated infant mortality rate (deaths in the first year of life/1000 live births). Numbers of deaths are small and year on year variation at individual local authority area level is likely to be due to chance.

Immediate cause of perinatal and infant death

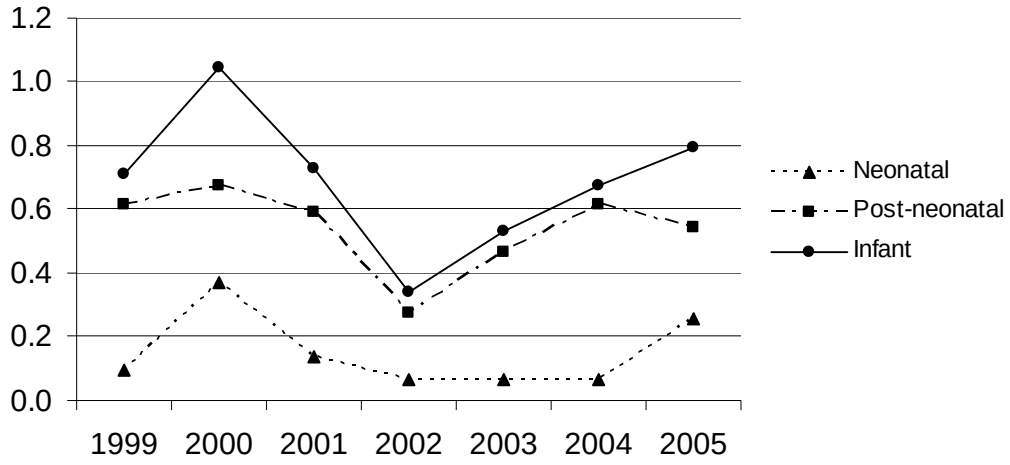
Table 2.5 gives cause of death using the Extended Wigglesworth classification and perinatal and infant mortality rates. The major contributor to perinatal mortality remains "antepartum death", in the main unexplained antepartum stillbirth. Both congenital malformation and immaturity also contribute as significant causes. Concerns about the lack of improvement in unexplained antepartum stillbirth rates were again highlighted at the PMS Annual Meeting in March 2006. Chapter 3 describes a detailed analysis of late fetal death in relation to risk factors.

The most important cause of infant mortality is malformation followed by immaturity, Sudden Infant Death Syndrome (SIDS) and infection.

SIDS

The contribution of SIDS reduced markedly from a rate of 1.8/1000 live births in 1989-1991 to 0.7/1000 live births in 2000-2002 and 0.5/1000 live births in 2003-2005. Numbers show year on year variation (nine deaths in 2002; 13 deaths 2003; 20 deaths 2004; 20 deaths in 2005). Despite this, overall the prevalence rate of SIDS among neonatal, postneonatal and infant deaths in 2005 is similar to that recorded in 1999 (Figure 2.6).

Figure 2.6: Contribution of SIDS to neonatal, postneonatal and infant deaths per 1000 live births, 1999-2005



Investigating and managing Sudden Unexpected Death in Infancy across the region

Baroness Kennedy chaired a national working group that made recommendations for the investigation of sudden unexpected deaths in infancy which have been endorsed by national and Government agencies[2]. In November 2004 the RMSO convened a regional multi-agency meeting to discuss how best to implement the Kennedy report, given the local limitations of geography and resources. It was clear from the discussion at this meeting that the Police, Coroners, and paediatricians in this region recognised that some of the recommendations cannot be implemented as written because of constraints of resource or practicality. From that meeting, a multi-agency working group was convened and chaired by Mr Carney, the South Tyneside Coroner.

The principles that emerged from this work, and which are reproduced in Appendix 5, provide a framework for local operational guidelines. They are not exhaustive: they are simply those that are at variance with the Kennedy recommendations. These principles are relevant to the Police forces, Coroners and Health Trusts in North Cumbria, Northumberland, Tyne & Wear, Durham, Darlington and Teesside.

[2] *Sudden unexpected death in infancy. A multi-agency protocol for care and investigation.* The report of a working group convened by The Royal College of Pathologists and The Royal College of Paediatrics and Child Health. Further copies of this publication can be obtained from the Colleges' websites, www.rcpath.org and www.rcpch.ac.uk

Table 2.1: North East Region and Northern Region: Perinatal Deaths and Perinatal Mortality Rates 2003, 2004 & 2005 and 3 year rolling average Perinatal Mortality Rates 2002-2004 and 2003–2005, by Local Authority

Local Authority	Registered Total Births (ONS)			Number of Perinatal Deaths (PMS)			PERINATAL MORTALITY RATE (per 1000 Total Births)				
	2003	2004	2005	2003	2004	2005	2003	2004	2005	2002/04	2003/05
Hartlepool	1067	1080	1122	7	8	8	6.6	7.4	7.1	7.9	7.0
Stockton on Tees	2127	2129	2251	20	15	13	9.4	7.0	5.8	7.5	7.4
Middlesbrough	1795	1857	1933	14	12	20	7.8	6.5	10.3	8.0	8.2
Redcar & Cleveland	1454	1519	1587	11	15	13	7.6	9.9	8.2	8.1	8.6
Darlington	1184	1263	1224	6	12	9	5.1	8.7	7.4	7.0	7.1
County Durham	4963	5375	5218	47	43	46	9.5	8.0	8.8	8.5	8.8
Sunderland	3026	2988	3093	22	37	29	7.3	12.4	9.4	9.4	9.7
South Tyneside	1531	1544	1533	11	8	8	7.2	5.2	5.2	6.6	5.9
Gateshead	2031	2136	2129	19	12	21	9.4	5.6	9.9	7.3	8.3
North Tyneside	2114	2172	2288	14	19	18	6.6	8.7	7.9	7.9	7.7
Newcastle	2913	2943	2998	25	29	25	8.6	9.9	8.3	9.8	8.9
Northumberland	2950	2966	3035	21	14	18	7.1	4.7	5.9	7.1	5.9
NORTH EAST REGION	**27155**	**27972**	**28411**	**217**	**224**	**228**	**8.0**	**8.0**	**8.0**	**8.4**	**8.0**
Allerdale	902	888	902	4	5	9	4.4	5.6	10.0	5.7	6.7
Carlisle	1100	1158	1113	7	9	12	6.4	7.8	10.8	7.6	8.3
Copeland	696	693	726	9	5	4	12.9	7.2	5.5	11.2	8.5
Eden	476	491	459	6	2	4	12.6	4.1	8.7	7.2	8.5
NORTHERN REGION	**30329**	**31202**	**31611**	**243**	**245**	**257**	**8.0**	**7.9**	**8.1**	**8.1**	**8.0**

Table 2.2: Northern Region 2004 & 2005: 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 2004 & 2005

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		
	04	05	04	05	04	05	04	05	2004	2005	2003-05	2004	2005	2003-05
Hartlepool	8	8	8	7	4	6	3	5	3.7	5.3	4.2	2.8	4.5	3.1
Stockton on Tees	15	13	13	9	11	6	10	6	5.2	2.7	4.4	4.7	2.7	3.7
Middlesbrough	12	20	11	15	8	12	5	10	4.3	6.2	5.5	2.7	5.2	3.7
Redcar & Cleveland	15	13	14	10	10	10	9	9	6.6	6.3	5.0	5.9	5.7	4.6
Darlington	12	9	8	6	6	5	4	4	4.8	4.1	3.2	3.2	3.3	2.4
County Durham	43	46	41	40	29	27	25	23	5.4	5.2	5.4	4.7	4.4	4.5
Sunderland	37	29	32	24	27	15	24	15	9.0	4.8	6.1	8.0	4.8	5.6
South Tyneside	8	8	6	5	4	2	2	1	2.6	1.3	3.5	1.3	0.7	2.8
Gateshead	12	21	11	18	7	9	6	8	3.3	4.2	4.3	2.8	3.8	4.0
North Tyneside	19	18	16	16	8	12	5	11	3.7	5.2	4.4	2.3	4.8	3.8
Newcastle	29	25	25	22	19	16	18	14	6.5	5.3	5.8	6.1	4.7	4.6
Northumberland	14	18	12	15	9	9	8	8	5.7	3.0	4.1	2.7	2.6	2.3
NORTH EAST REGION	224	228	197	187	142	129	119	114	5.1	4.5	4.8	4.3	4.0	4.0
Allerdale	5	9	4	9	3	6	3	6	3.4	6.7	4.1	3.4	6.7	3.7
Carlisle	9	12	9	10	8	8	7	7	6.9	7.2	6.2	6.0	6.3	5.6
Copeland	5	4	4	3	3	2	2	2	4.3	2.8	4.8	2.9	2.8	4.3
Eden	2	4	2	4	1	3	0	3	2.0	6.5	4.9	0.0	6.5	4.3
NORTHERN REGION	245	257	216	213	157	148	131	132	5.0	4.7	4.8	4.2	4.2	4.1

Table 2.3: Northern Region 2004 & 2005: 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
	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2003-2005
Hartlepool	1691	1678	6(2)	6	0	4	0	2	3.5	6.0	2.4	6.0	5.5
North Tees	2012	2115	11(2)	10(2)	5(1)	4(1)	1	2	8.0	6.6	6.5	5.2	6.5
James Cook	3694	3714	24(3)	28(1)	6(1)	7(1)	6(1)	5	8.1	9.4	7.0	8.9	7.6
Guisborough	71	132	0	0	0	0	0	0	-	-	-	-	-
Darlington	2105	2277	16(4)	14(5)	6(1)	5(2)	1	2	10.5	8.3	8.1	5.3	6.2
B. Auckland*	777	376	3	0	1	0	0	0	5.1	0	5.1	0	4.6
UHND Durham	2481	2529	14(1)	17(1)	3	3	0	3	6.9	7.9	6.4	7.5	6.5
Sunderland	3124	3328	27(3)	23(1)	13(2)	7(2)	3(2)	2(1)	12.8	9.0	11.2	8.1	8.7
S. Tyneside	1490	1467	3	3	1	2	0	1	2.7	3.4	2.7	3.4	3.8
Gateshead	1769	1682	6	8	3	6(2)	1	0	5.1	8.3	5.1	7.1	6.5
Newcastle	4913	5176	40(8)	32(9)	12(8)	15(7)	6(3)	8(2)	10.6	9.1	7.3	6.0	7.1
N. Tyneside	1763	1762	9	9	5	2	2	1	7.9	6.2	7.9	6.2	5.5
Ashington	1891	1934	8(1)	7	0	6	0	0	4.2	6.7	3.7	6.7	5.9
Berwick	23	20	0	0	0	0	0	0	-	-	-	-	-
Alnwick	40	62	0	0	0	0	0	0	-	-	-	-	-
Hexham	325	286	0	0	0	0	0	0	-	-	-	-	-
Carlisle	1750	1735	8	10	2	6 (2)	2	1	5.7	9.2	5.7	8.1	6.5
West Cumberland	1267	1282	6	8	0	2	0	0	4.7	7.8	4.7	7.8	6.9
Penrith	52	84	0	0	0	0	0	0	-	-	-	-	-
Totals	**31238**	**31639**	**181**	**175**	**57**	**69**	**22**	**27**	**7.6**	**7.7**	**6.5**	**6.6**	**6.6**

* 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 2004 & 2005. Infant Mortality rate by Local Authority 2004 & 2005 and for 2003-2005

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		
	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	03/05
Hartlepool	1080	1122	3	6	7	6	1	2	0	1	3	0	3.7	2.7	4.3
Stockton on Tees	2129	2251	4	10	11	10	4	3	3	3	3	2	4.7	3.6	4.6
Middlesbrough	1857	1933	14	4	9	17	3	3	2	3	4	7	4.9	6.8	5.8
Redcar & Cleveland	1519	1587	4	6	11	10	4	3	4	2	3	5	7.3	6.3	6.8
Darlington	1263	1224	4	6	9	5	3	4	0	1	2	2	4.0	5.7	4.6
County Durham	5375	5218	21	24	32	30	11	16	2	5	7	12	3.7	6.4	5.0
Sunderland	2988	3093	17	13	25	25	12	4	1	3	7	3	6.7	3.3	5.5
South Tyneside	1544	1533	10	4	4	4	4	4	0	1	1	2	3.2	4.6	3.7
Gateshead	2136	2129	5	5	9	12	3	9	2	2	3	2	3.8	6.1	5.6
North Tyneside	2172	2288	3	8	14	15	5	3	3	1	1	4	4.2	3.5	3.7
Newcastle	2943	2998	8	11	25	19	4	6	4	3	8	8	5.5	5.7	5.2
Northumberland	2966	3035	14	4	13	11	1	7	1	1	3	4	1.7	3.9	2.9
NORTH EAST REGION	**27972**	**28411**	**107**	**101**	**169**	**164**	**55**	**64**	**22**	**26**	**45**	**51**	**4.4**	**5.0**	**4.8**
Allerdale	888	902	3	2	5	7	0	2	1	0	5	2	6.8	4.5	4.9
Carlisle	1158	1113	1	12	6	6	3	6	0	1	2	1	4.3	7.2	5.9
Copeland	693	726	1	2	4	2	1	2	0	0	2	0	4.4	2.8	5.8
Eden	491	459	1	1	0	3	2	1	1	0	0	2	6.2	6.6	5.7
NORTHERN REGION	**31202**	**31611**	**113**	**118**	**184**	**182**	**61**	**75**	**24**	**27**	**54**	**56**	**4.5**	**5.0**	**4.9**

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 2003-2005

CAUSE OF DEATH	PERINATAL MORTALITY			INFANT MORTALITY		
	Deaths 2005	Average rate 2002-2004	Average rate 2003-2005	Deaths 2005	Average rate 2002-2004	Average rate 2003-2005
Malformation	37	1.4	1.3	48	1.3	1.4
Antepartum death (unexplained)	127	4.0	3.9	2[c]	0.0	0.05
Intrapartum anoxia/trauma	26	0.8	0.8	11	0.4	0.4
Immaturity	35	0.9	1.0	44	1.2	1.3
Infection (including NEC[a])	16	0.5	0.5	16	0.9	0.7
SIDS[b]	1	0	0.01	20	0.4	0.5
Accident-non IP trauma	0	0	0	2	0.0	0.05
Other specific causes	13	0.6	0.5	9	0.3	0.3
Unclassifiable	2	0	0.05	6	0.04	0.1
All Causes	**257**	**8.1**	**8.0**	**158**	**4.7**	**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. CHANGING PATTERNS OF STILLBIRTH

Introduction

This chapter presents selected findings from a detailed exploration of regional trends in stillbirth over the last two decades. This study was prompted by the observation that improvements in stillbirth rates appeared to have stalled in recent years. A key aim was to explore whether adverse changes in the risk profile of the population had contributed to maintaining high stillbirth rates.

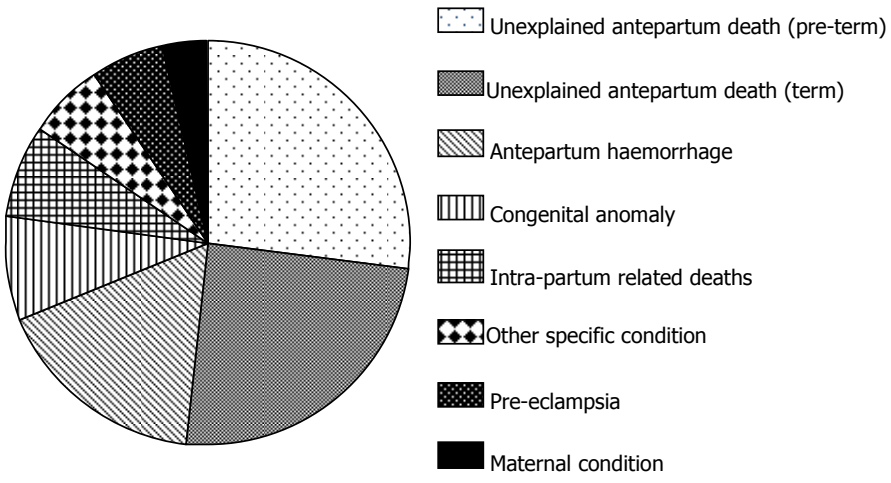
Methods

All stillbirths between 1982 and 2000 were identified from the Northern Perinatal Mortality Survey. Denominator data on live births was obtained from ONS, and included birthweight in 500g categories, maternal age group and whether the birth was from a multiple pregnancy. Only fetal deaths delivered at 28 weeks or more were included in the study, to maintain a consistent definition over time (the legal definition of stillbirth changed in 1992 to include fetal deaths at 24 or more weeks gestation). In addition, we excluded births (live and still) weighing less than 500g.

Stillbirth characteristics

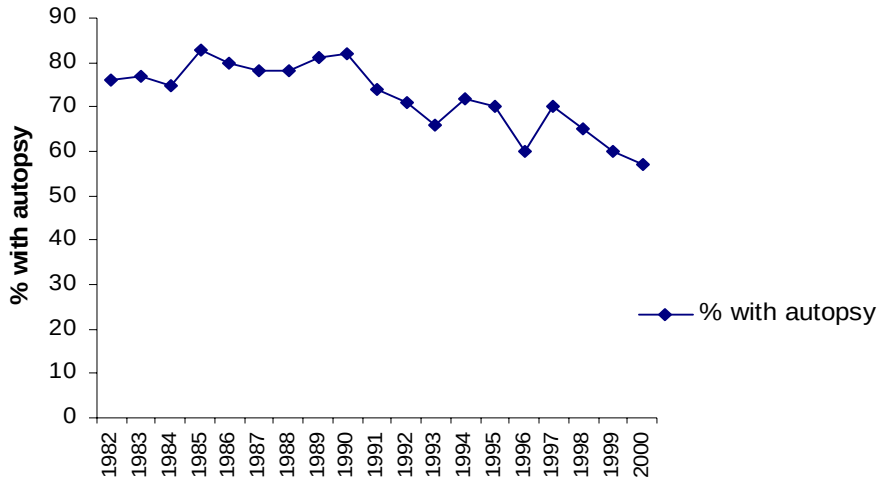
The overall rate of stillbirth at 28 weeks or more was 4.9 per 1000 births. Figure 3.1 shows the breakdown by cause; around half of all stillbirths were unexplained antepartum deaths, and of these about half were delivered preterm (<37 weeks' gestation). Other important causes were congenital anomalies, antepartum haemorrhage and pre-eclampsia.

Figure 3.1: Cause of stillbirth (≥ 28 weeks)



There was a marked reduction in the proportion of stillbirths for which post-mortem was undertaken. A high rate was maintained during the 1980s, but this declined sharply during the 1990s (figure 3.2). The post-mortem autopsy rate was 79% in 1982-1990 and 67% in 1991-2000.

Figure 3.2: Autopsy by year of delivery



Trends in stillbirth rate

The overall stillbirth rate at 28 or more weeks gestation declined from **6.1** per 1000 births in 1982-85 to **4.0** in 1996-2000, a reduction of around one third (figure 3.3). There were major differences in the reduction in stillbirths within different cause categories (table 3.1). Nearly all of the reduction in stillbirth rate was attributable to reductions in deaths due to congenital anomalies, intrapartum related deaths, pre-eclampsia and antepartum haemorrhage. In contrast, there was no significant reduction in unexplained antepartum stillbirths. The proportion of unexplained antepartum deaths increased from 48% in 1982-1990 to 56% in 1991-2000.

Figure 3.3: Trends in stillbirth rate 1982-2000

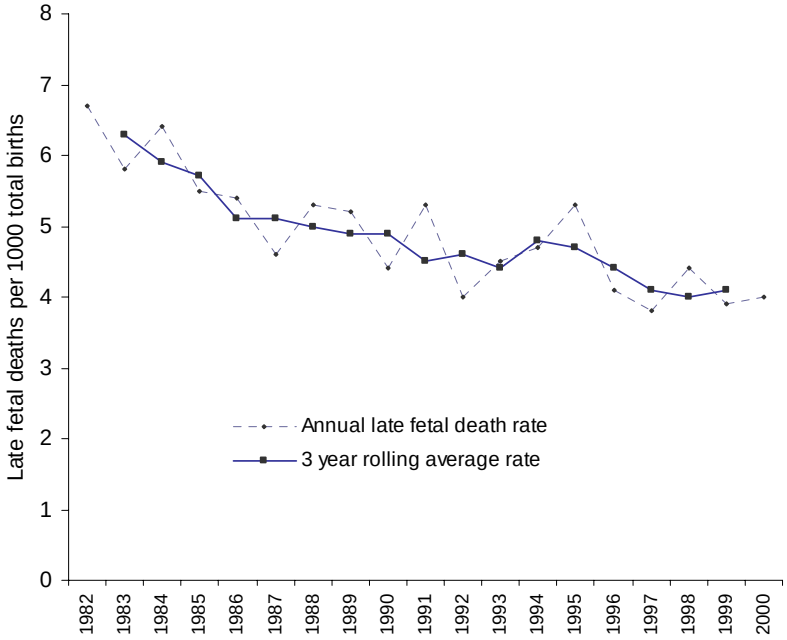


Table 3.1 Cause specific stillbirth rates and odds ratio for reduction over time

	1982-1990 n=343,226	1991-2000 n=343,055	Odds ratio (95% CI)
Congenital anomaly	5.0 (170)	2.9 (100)	0.59 (0.46-0.75)
Antepartum haemorrhage	10.1 (346)	6.9 (238)	0.69 (0.58-0.81)
Pre-eclampsia	3.7 (127)	2.0 (70)	0.55 (0.41-0.74)
Intrapartum-related deaths:	4.9 (169)	2.4 (82)	0.49 (0.37-0.63)
Malpresentation/disproportion	*0.9 (31)*	*0.2 (8)*	*0.26 (0.12-0.56)*
Cord prolapse or compression	*0.6 (21)*	*0.2 (8)*	*0.38 (0.17-0.86)*
Uterine rupture	*0.1 (4)*	*0.1 (4)*	*1.00 (0.25-4.00)*
Unexplained intrapartum death	*3.3 (113)*	*1.8 (62)*	*0.55 (0.40-0.75)*
Unexplained antepartum death	26.2 (899)	24.6 (844)	0.94 (0.85-1.03)
Preterm (<37 weeks)	*13.7 (471)*	*12.9 (442)*	*0.94 (0.82-1.07)*
Term	*12.5 (428)*	*11.7 (402)*	*0.94 (0.82-1.08)*
Maternal conditions:	2.0 (69)	1.4 (49)	0.71 (0.49-1.02)
Hypertension	*0.7 (23)*	*0.4 (13)*	*0.57 (0.27-1.12)*
Diabetes	*1.0 (34)*	*0.7 (23)*	*0.68 (0.40-1.15)*
Other	*0.3 (12)*	*0.4 (13)*	*1.08 (0.49-2.38)*
Other specific conditions:	2.7 (91)	3.8 (132)	1.45 (1.11-1.90)
Infection	*0.4 (15)*	*0.9 (31)*	*2.07 (1.12-3.83)*
Iso-immunisation	*0.4 (15)*	*0.3 (9)*	*0.60 (0.26-1.38)*
Twin-twin transfusion syndrome	*0.6 (22)*	*0.6 (19)*	*0.86 (0.47-1.60)*
Fetal hydrops	*0.3 (10)*	*0.4 (14)*	*1.40 (0.62-3.15)*
Fetal blood loss	*0.1 (5)*	*0.4 (13)*	*2.60 (0.93-7.30)*
Fetal tumour	*0.1 (4)*	*0.1 (3)*	*0.75 (0.17-3.35)*
Antepartum death with cord compression	*0.4 (15)*	*0.9 (30)*	*2.00 (1.07-3.72)*
Other and unclassified	0.1 (5)	0.4 (13)	2.60 (0.93-7.30)
All causes	**54.5 (1871)**	**44.2 (1515)**	**0.81 (0.76-0.87)**

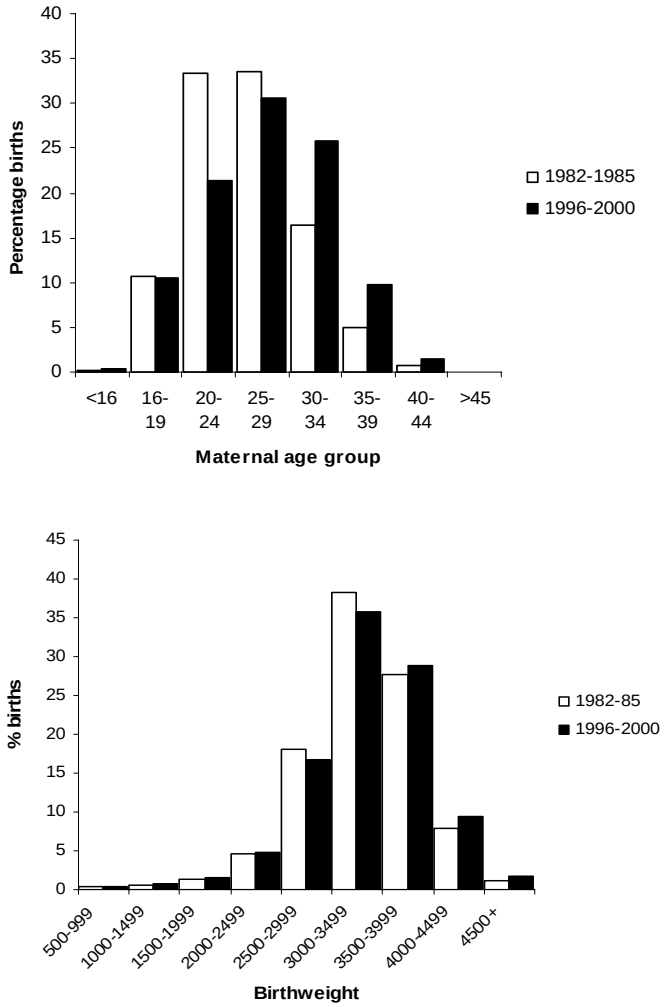
There were greater reductions in stillbirth rates within higher risk categories. Stillbirth rates fell by around 55% in multiple births compared to 33% for singletons. There were substantial reductions within low birthweight categories, particularly for birthweights less than 2000g, but no significant reduction in stillbirth rates at birthweights 3500g or more.

Thus, overall, stillbirth rates declined substantially for identifiable causes and for high risk groups. In contrast, unexplained antepartum stillbirths of good birthweight remained notably resistant to change. This may reflect the fact that low risk women with no obvious pregnancy complications receive less intense antenatal surveillance.

Changes in risk factors and their impact on stillbirth rates

Over the study period, the characteristics of the birth population changed substantially. The most significant demographic shift is increasing maternal age (figure 3.4). There have also been changes in birthweight. There are two contrasting trends; mean birthweight has risen, but there has also been an increase in low birthweight births, which are at greatly increased risk of stillbirth (figure 3.4). Multiple births also increased by about one third over the study period.

Figure 3.4: Changes in maternal age and birthweight



These trends have all resulted in increases in the proportion of births in higher risk categories. This would tend to increase stillbirth rates. To quantify this, and to assess what the stillbirth rate might have been had there been no change in the risk profile of the population, we calculated rates that were standardised for maternal age, birthweight and multiple births (table 2). This showed that if there had been no change in maternal age, birthweight, infant gender and multiple births, then the expected stillbirth rate would have been 3.7 per 1000 rather than 4.1 per 1000 – about 10% lower.

Therefore, changes in the underlying population risk profile mean that the stillbirth rate is about 10% higher than it might otherwise have been. However, this effect is small compared with the overall decline in stillbirth rates of about one third. Hence, changes in

the underlying population risk profile have had only a small influence on population stillbirth rates.

Table 3.2: Stillbirth rates for 1998-2000, standardised to the 1982-84 population

	Stillbirth rate (95% CI)
Observed 1982-84	6.3
Observed 1998-2000	4.1
1998-2000 rate standardised for single variables:	
Maternal age	4.0 (3.5-4.4)
Multiplicity	4.0 (3.6-4.5)
Gender	4.1 (3.7-4.5)
Birthweight	3.8 (3.4-4.2)
1998-2000 rates standardised for multiple variables:	
Maternal age, multiplicity, gender	3.9 (3.5-4.4)
Maternal age, multiplicity, gender and birthweight	3.7 (3.3-4.1)

*Actual for observed rates, expected for standardised rates

Conclusions

- Stillbirth rates (28 or more weeks) declined by about one third during the 1980s and 1990s.
- The improvement in stillbirth rates was mainly a result of reductions in stillbirth due to congenital anomaly, pre-eclampsia, antepartum haemorrhage and intrapartum related deaths.
- There was a greater improvement in stillbirth rates in multiple births and in low birthweight categories than for lower risk categories.
- There were adverse changes in the population risk profile, with increasing proportions of older mothers, multiple births, and low birthweight babies.
- These adverse changes had only a small impact on population stillbirth rates because of the marked improvements in stillbirth rates in high risk categories.
- The main challenge to further decline in stillbirths is the continuing high rate of unexplained antepartum stillbirth at term, in women with no apparent risk factors or complications.

4. POST-MORTEM RATES

Post-mortem rates

Post-mortem rates for the region and for individual units are presented in table 4.1 (overpage). The numbers and rates are calculated from the numbers of deaths within a unit.

Post-mortem rates by outcome in 2005 (table 4.2) are similar to rates in 2004, except for a higher rate of post-mortems following late neonatal deaths (NND).

Table 4.2: 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	PostNND
2001	58	47	57	41	48	43	58
2002	54	16	50	23	37	27	43
2003	50	50	50	37	39	37	59
2004	51	33	50	30	35	31	57
2005	55	33	52	31	63	39	54

Table 4.1: 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 (%)			
	2004	2005	2004	2005	2002	2003	2004	2005	2004	2005	2004	2005	2002	2003	2004	2005
Hartlepool	11	16	3	11	67	44	27	69	6	10	0	7	67	46	0	70
North Tees	23	30	12	13	30	49	52	57	16	14	7	7	25	60	44	50
James Cook	62	59	32	30	42	35	52	51	30	35	17	13	38	15	57	37
Darlington	36	40	11	15	60	63	31	38	22	19	7	7	50	57	32	37
Bishop Auckland*	7	0	4	0	29	16	57	N/A	4	0	3	0	13	17	75	N/A
UHND Durham	29	41	19	18	79	35	66	44	17	20	8	8	83	31	47	40
Sunderland	65	52	34	32	53	75	52	62	40	30	20	19	56	67	50	63
South Tyneside	13	11	5	5	72	73	39	46	4	5	2	2	56	78	50	40
Gateshead	18	20	8	12	46	67	44	60	9	14	4	7	40	75	44	50
RVI Newcastle	93	85	46	40	52	44	50	47	52	47	27	21	50	47	52	45
North Tyneside	19	19	9	11	50	58	47	58	14	11	5	5	46	80	36	46
Wansbeck	17	18	11	8	37	48	65	44	8	13	5	4	30	44	63	31
Hexham	0	0	N/A	0	20	50	N/A	N/A	0	0	N/A	N/A	0	100	N/A	N/A
Carlisle	18	33	6	17	21	54	33	52	10	16	3	9	30	36	30	56
West Cumberland	14	16	6	6	80	38	43	38	6	10	2	4	75	40	33	40
Home	7	9	1	7	50	67	14	78	5	7	0	5	0	67	0	71
Out of Region	4	5	0	0	0	17	0	0	2	3	0	0	0	0	0	0
TOTALS	**436**	**454**	**207**	**225**	**49**	**49**	**47**	**50**	**245**	**254**	**110**	**118**	**45**	**46**	**45**	**47**

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

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

- The CEMACH child death review project;
- The CEMACH diabetes project;
- The maternal death enquiry

CEMACH Child Death Review project

The Child Death Review feasibility study is being carried out by the Confidential Enquiry into Maternal and Child Health (CEMACH) in the South West, West Midlands, and North East regions, Wales and Northern Ireland.

The Child Death Review will seek to obtain an overview of all child deaths from 28 days to 18 years over a one year period (2006). Core data on all child deaths identified in these regions will be collected and detailed multi-agency reviews will be conducted on a subset of deaths with a focus on identifying preventable and avoidable factors. The protocol is available on the CEMACH website.[3]

Data collection on child deaths started in the North East in September 2005 (as a pre pilot) and will continue until December 2006. A notification process is in place and all child deaths from age **29 days to 17 years 364 days** should be notified to Marjorie Renwick at the RMSO.

The *Working Together*[4] guidance requires all local authority 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.

CEMACH process

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

Requests for core data sets to be completed and requests for GP records are sent out immediately a notification is received. Once the core dataset[5] is completed this is entered

[3] www.cemach.org.uk

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

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

into the database. The RMSO is notified of cases which have been randomised and full case notes are requested on these children. Case notes are fully anonymised (all identifying information in relation to the child and family is removed, staff names removed and titles/grades retained, all unit identifiers removed). Anonymised notes are then sent to CEMACH central office for distribution to other regions for confidential enquiry i.e. regions do not review local cases.

The enquiry panel process has been piloted and has just commenced. Each panel has an agreed membership (a core membership plus additional specialists dependant on the types of death being reviewed) and a standardised proforma is used for the panel process.

CEMACH Diabetes Project

The CEMACH diabetes project is the largest study of diabetes in pregnancy ever conducted. It included data for 3808 women with diabetes who delivered or booked in 231 hospitals in England, Wales and Northern Ireland between 1 March 2002 and 28 February 2003. Data were collected on standards of care for these women and their babies with the aim of evaluating pregnancy outcomes and quality of care. The national report *Pregnancy in women with type 1 and type 2 diabetes in 2002-2003*[6] was launched at a joint study day with the Royal College of Obstetricians and Gynaecologists in London on 11 October 2005.

An update on the regional confidential enquiry process was included in last year's report, with the final panel (of the 15 conducted) being held in October 2005.

Neonatal enquiries

In the neonatal enquiry, pregnancies were randomly sampled from the diabetes cohort database of 3808 pregnancies after excluding deaths, fetal congenital anomalies, multiple births and gestation at delivery less than 37+0. The case definition for the neonatal enquiry was therefore all term pregnancies in women with diabetes resulting in a normally formed baby surviving to 28 days after delivery. One hundred and thirty-two babies met this case definition. Neonatal medical records were not available for 13 babies, leaving 119 babies for enquiry. These babies were then divided into two groups for further comparative analysis:

- Babies who were initially admitted with their mother to the postnatal ward or to a transitional care unit, or who stayed with their mother on the labour ward or a maternal high dependency unit.
- Babies who were initially admitted to a neonatal unit for special care.

Twelve cases were identified for enquiry in the Northern Region and two panel meetings were convened looking at six cases per meeting. Panel consisted of two paediatricians, two neonatal practitioners and two midwives. One of the main findings of the panel members was the inability to find a summary of timing of feeds and blood sugar monitoring in the neonatal notes. Clinicians queried how easy it was to find this information in neonatal notes in their own units and reported back to the Diabetes Steering Group. At the July meeting the audience acknowledged the need for a 'baby feeding chart'. The process of adopting a chart (figure 5.1) in all units is now being taken forward by the Local Supervising Authority (LSA) Midwife through the Supervisor of Midwives in each maternity unit.

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[6] www.cemach.org.uk/publications/CEMACHDiabetesOctober2005.pdf

Figure 5.1 Newborn feed chart

Newborn Feed Chart

Hospital _____

BABY'S NAME _____

BABY'S NHS NUMBER _____

DATE OF BIRTH / TIME _____

WEIGHT _____ CENTILE _____

Infants of Diabetic Mothers: are at risk of hypoglycemia

- First feed within 2hrs preferable on labour ward; aim to feed 3-4 hrly.
- Check glucose hemocue before 2nd feed unless symptomatic
  If glucose < 2.6 inform ANNP/Dr
- Check glucose hemocue before 4th feed
  If glucose < 2.6 inform ANNP/Dr
- Check a capillary haematocrit with the 2nd glucose
  Capillary HCT result

Always encourage breast feeding, and offer skin to skin contact with mother on labour ward. Discuss feeding regime with mother.

DATE	TIME/AGE	PRE FEED BLOOD GLUCOSE	ARTIFICIAL FEED BREAST FEED LENGTH	TEMP	INSTRUCTIONS	COMMENTS SIGN

IF ADDITIONAL RECORDING NECESSARY USE TRANSITIONAL CARE CHART

Maternal deaths

It is a national requirement that all maternal deaths should be subject to this 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 for research and audit at a local and national level;
- To review methodologies for enquiry into maternal deaths.

Definition of maternal death

A maternal death is defined as <u>any</u> death that occurs during or within one year of pregnancy, childbirth or abortion.

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 MDR1.

The table below summarises which maternal death cases are required to undergo the full assessment process. In effect most deaths which occur up to 120 days after delivery require a full assessment, as do certain categories of death which occur after this. In most other cases where women die between 120-365 days after delivery only a basic assessment is required.

A full assessment comprises:

- Completion of MDR1 baseline dataset sections 1, 2, 3 and 8
- Completion of all relevant sections 4 - 16 by clinicians involved in care
- Request for clinical documentation using checklist on page 1

- Attachment of local enquiry report and action points
- Attachment of PM report and full anaesthetic records where applicable
- Regional assessment
- Central assessment

Those cases not requiring the full assessment **must** have the MDR1 baseline dataset sections 1, 2, 3 and 8 completed.

Full assessment

A. All deaths from any cause that occur during pregnancy or up to, and including 4 months (120 days) after delivery, ectopic, TOP or miscarriage.

There are three categories (to be finally determined by the central assessors):

Direct: i.e. from obstetric or anaesthetic causes

Indirect: i.e. pre-existing or new medical or psychological/ mental health problems related to, or aggravated by pregnancy
Also include:
Cancer of breast, cervix or ovary
Substance misuse
Suicide –please include suicides **up to 6 months following delivery** (182 days) if there was a known history of psychiatric illness or substance misuse before and/or during pregnancy*

Coincidental: (apparently unrelated but often contain valuable public health information relating e.g. to use of seat belts, violence, substance misuse or murder)
Include:
RTA's during pregnancy where the woman was the driver or passenger (as related to seat belt use, although do not include these deaths if before booking)
Murder by a family member /partner
Substance misuse
All other cancers

Rationale

Even though the internationally defined maternal mortality rate/ratio is limited to deaths up to and including 42 days after delivery, the Enquiry has always found many of the deaths occurring within the first few months to be equally important.

* 4-6 months deaths: only midwifery, obstetric, GP, psychiatric and pathology notes required (not additional agencies')

Full assessment

B. All deaths between 120 days and 365 days after delivery which occur from:

- **Any underlying direct obstetric or anaesthetic cause of death** (e.g. a PPH which led to prolonged life support and final death from pneumonia in ICU)
- **cardiomyopathy**
- **congenital heart disease or cystic fibrosis if death due to an event or problems identified during pregnancy or in 42 days following delivery – make reasonable attempt to get cardiac notes (2 requests to cardiac unit)**
- **cancer of the breast, cervix or ovary**

Rationale

These are the women whose deaths may be either directly due to a condition which although related to pregnancy may not occur until some months later e.g. puerperal cardiomyopathy. They do not respect the international 42 day cut off point but are entirely due to pregnancy.

Hormone dependant malignancies are often either aggravated, or missed, in pregnancy and, sometimes wrong advice is given in pre-conception counselling about time scales for delaying pregnancy after treatment.

Full assessment

C. Any other death occurring after 4 months post delivery and for which the CEMACH regional manager has information that might suggest it contains lessons (good or bad) for this enquiry.

Some may contain valuable lessons about management or identification of the underlying problems during or after pregnancy, e.g. deaths from diseases that should have easily been picked up, and perhaps remedied, in pregnancy or women with malignancies for whom care would have been provided more quickly.

MDR1 baseline dataset only

All deaths from other causes, including ONS notifications, that occur between 120 -365 days following delivery, unless otherwise directed by the CEMACH Director, who is also readily available to give advice in cases of uncertainty.

All RTAs and pedestrian or other accidents where the woman was not the driver or passenger or over which she had no control, which occur **at any time** during pregnancy or after delivery.

Additional cases to include

Women who have received fertility treatment not ending in pregnancy, but where death occurred as a result of having had fertility treatment.
Please obtain:

- Fertility clinic report – including a brief summary of treatment received
- Pathology report

Cases not included

UK women who die abroad, unless major lessons apparent from the care she received in the UK.

6. NORTHERN DIABETIC PREGNANCY SURVEY

Introduction

The Northern Diabetic Pregnancy Survey (NDPS) has been running since 1995 and has been managed from the RMSO since 1999. NDPS collects data on pregnancy in women with pre pregnancy diabetes. The total number of pregnancies and the outcomes are shown in table 6.1.

Table 6.1: Outcome of Diabetic Pregnancies 1995-2005 (* Data for 2005 are provisional)

Outcome	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005*
Women Registered	124	127	133	131	136	128	130	141	155	170	157
Live births	97	100	97	102	113	111	102	122	137	154	133
Sp. abort.<20 weeks gestation[1]	19	23	28	20	20	13	20	18	14	15	14
Sp. abort. 20–23^{+6} weeks gestation	0	1	3	0	0	0	0	0	0	0	1
Terminations	6	3	3	3	2	2	8	2	4	0	3
Antepartum Stillbirth	3	3	2	5	5	2	1	3	2	3	6
Intrapartum Stillbirth	0	0	1	1	0	0	0	0	0	0	1
Early Neonatal Death (0-6 days)	2	0	0	3	0	1	0	0	2	0	0
Late Neonatal Death (7-28 days)	2	0	1	0	0	0	0	1	0	0	0
Postneonatal Deaths (29-365 days)	0	0	0	0	1	1	0	1	1	2	0
Alive at 1 year	93	100	96	99	112	109	102	120	134	152	133
Total Outcomes	125[2]	130[3]	134[4]	131	140[5]	128	131[6]	145[7]	157[8]	172[9]	158[10]
Perinatal Mortality Rate	50.0	29.1	30.0	83.3	42.4	26.5	9.7	24.0	28.8	19.1	50.0

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. 2 sets of twins (all LB)

Audit of units against standards of care

A detailed audit was undertaken in 2004 comparing units against the standards of care for pre pregnancy diabetes. Findings were detailed in last year's annual report and in a paper published by NEPHO.[7]

[7] BAILEY K, LEWIS-BARNED N & CRESSWELL PA. *Occasional Paper No 19 – Northern Diabetes in Pregnancy Survey – Audit of Units Against Standards of Care*. North East PHO. 2005.

Standards for gestational diabetes: update on progress

What is gestational diabetes?

Gestational diabetes is diabetes or impaired glucose tolerance that is first recognised during pregnancy. In most women, the disturbed glucose metabolism returns to normal after pregnancy, but there is a substantial risk of the development of type 2 diabetes later in life. Gestational diabetes is also associated with increased risk of adverse perinatal outcomes, but is not thought to be associated with congenital anomalies because the impairment of glucose metabolism develops later in pregnancy, after the most critical period of fetal development. Gestational diabetes is more common in obese and overweight women, in women of Asian or Black ethnicity, in older women and those with a family history of type 2 diabetes. Hence, the obesity epidemic is anticipated to lead to a rise in prevalence.

Why develop regional standards for gestational diabetes?

Until recently, evidence that screening and treating gestational diabetes improved outcomes was lacking. NICE guidance explicitly recommended against *routine* screening for gestational diabetes.[8] In 2005, however, the ACHOIS[9,10] trial was published which provided evidence that detection and active management of mild glucose intolerance in pregnancy improved outcomes. The implications of the trial continue to be debated, but at a national level NICE is reviewing diabetes in pregnancy, including the issue of gestational diabetes. Clinicians across the Northern Region are in agreement that gestational diabetes is an important issue that should be reviewed with a view to developing a co-ordinated approach.

What has been happening?

The NDPS Steering Group of the RMSO agreed to set up a small working party to look at the issues. Initially a survey was undertaken of current practice throughout the region, and this was discussed at the RMSO Summer Workshop on diabetes in pregnancy on 4 July 2006. Whilst it revealed wide variations in current approaches to screening and managing gestational diabetes, there was a broad consensus that further work should be done to develop draft standards of care. The first draft standards document was sent out for consultation in August and September. A half day conference was held on 24 November 2006 to refine the standards, with hopeful implementation in 2007. Our aim is to agree a regional approach to standards of care for gestational diabetes, and to extend the data collection for the NDPS to encompass pregnancies complicated by gestational diabetes. This will enable us to understand better the current care and outcomes of pregnancy experienced by this important and growing group of women.

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[8] SCOTT D, LOVEMAN E, MCINTYRE L, WAUGH N. Screening for gestational diabetes: a systematic review and economic evaluation. *Health Technology Assessment*, 2002.

[9] CROWTHER C, HILLER J, MOSS J, MCPHEE A, JEFFRIES W, ROBINSON J. Effect of treatment of gestational diabetes mellitus on pregnancy outcomes. *New England Journal of Medicine* 2005;352:2477-2468.

[10] FRASER R. Gestational diabetes: after the ACHOIS trial. *Diabetic Medicine* 2006;23:1-27.

7. MATERNITY CARE

Delivery statistics

The delivery statistics supplied by the individual units are shown in table 7.1. This year's figures show a picture of remarkable stability with no substantial change in any of the domains listed. There has been a small increase in births of less than 1% with the trend being an average flattening from its previous decline, rather than showing any sign of reversing. The full year effect of the change to midwifery- led care in the units at Hexham and Bishop Auckland has shown changes in births within the expected range for such a change. For the first time, there has been a significant increase in births at the long established midwifery- led units in Penrith and Alnwick supporting the view that where they exist, such units do offer a popular choice for delivery.

Measures of obstetric management continue to suggest wide variations in practice between units handling a similar casemix and units must begin to review their practice if this is to be justified.

Challenges

Units should now be at an advanced stage of planning for implementation of the 48 hour working week by August 2009 as required by the European Working Time Directive. It has been recognised that there will not be enough doctors in training to support current working patterns in the existing number of district general hospital maternity units.[12] It has been shown that replacing the acute care workforce with trained staff produces improved clinical outcomes.[13] At a time when recruitment into the speciality of obstetrics and gynaecology is at an all time low, the required expansion in consultant staff to maintain the current configuration of maternity units seems unlikely to happen. The merging of smaller units is inevitable. The planned mergers of North Tees with Hartlepool and North Tyneside with Wansbeck may provide a solution for others to follow although the full effect will not be seen until at least 2009. There are other models of service provision available which could be explored.[14]

The Future Role of the Consultant[12] published by the Royal College of Obstetricians and Gynaecologists sets challenging recommendations for increasing the amount of consultant time spent on delivery suite while also suggesting a withdrawal from out of hours working beyond the age of 55 years. Even if the hoped for expansion in consultant numbers were to be realised, these proposals provide a further drive towards the creation of a smaller number of larger units.

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[12] BLOTT M. The Future Role of the Consultant, a Working Party Report: London; Royal College of Obstetricians and Gynaecologist, 2005.

[13] NATIONAL MATERNITY SERVICES WORKFORCE PLANNING GROUP. Maternity service Workforce planning: a baseline report, 2005.

[14] NHS MODERNISING AGENCY. Survey of models of maternity care: Towards sustainable WTD compliant staffing and clinical network solutions; June, 2004.
www.rcog.org.uk/resources/Public/pdf/survey_of_models_maternity_care.pdf

The greatest challenge is to service commissioners who are asked to measure their local units against the standards set out in *Modernising Maternity Care – A Commissioning Toolkit for England*.[15] Even the small amount of data given in table 7.1 suggests that currently less than half of the units are likely to meet these standards.

The institutional model for providing maternity services is no longer sustainable. Cancer Networks have proved a successful, safe and efficient. By the time of the next Annual Report we may expect to describe the first maternity network.

[15] MATERNITY CARE WORKING PARTY. Modernising Maternity Care - A Commissioning Toolkit for England (2nd. Edition). The National Childbirth Trust, The Royal College of Midwives, The Royal College of Obstetricians and Gynaecologists. 2006
www.rcog.org.uk/resources/public/pdf/mmc_toolkit_06.pdf

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

Unit	Maternities		Births		Twins**		Breech		Induction		Normal vertex delivery		Assisted		Caesarean section	
	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005	2004	2005
Hartlepool	1670	1660	1691	1678	14 (0.8)	18 (1.1)	64 (3.8)	70 (4.2)	355 (21.0)	365 (22.0)	1228 (72.6)	1230 (74.1)	83 (4.9)	97 (5.8)	353 (20.9)	342 (20.6)
North Tees	1984	2084	2012	2115	28 (1.4)	31 (1.5)	48 (2.4)	79 (3.7)	433 (21.5)	367 (17.6)	1309 (65.1)	1457 (68.9)	236 (11.7)	219 (10.4)	348 (17.3)	360 (17.0)
James Cook University Hospital	3673	3649	3694	3714	58 (1.6)	65 (1.8)	168 (4.5)	158 (4.3)	830 (22.5)	896 (24.6)	2475 (67.0)	2645 (71.2)	416 (11.3)	386 (10.4)	778 (21.1)	765 (20.6)
Darlington	2026	2227	2105	2277	29 (1.4)	38 (1.7)	85 (4.0)	73 (3.2)	N/A	642 (28.8)	1377 (65.4)	1474 (64.7)	208 (9.9)	243 (10.7)	466 (21.2)	502 (22.0)
B. Auckland *	766	375	777	376	8 (1.0)	0 -	12 (1.5)	0 -	160 (20.6)	0 -	596 (76.7)	375 (99.7)	49 (6.3)	0 -	118 (15.2)	0 -
University Hospital of North Durham	2451	2508	2481	2512	30 (1.2)	47 (1.9)	83 (3.3)	84 (3.3)	490 (19.8)	574 (22.9)	1657 (66.8)	1562 (62.2)	291 (11.7)	394 (15.7)	508 (20.5)	565 (22.5)
Sunderland	3101	3298	3124	3328	45 (1.4)	49 (1.5)	94 (3.0)	113 (3.4)	473 (15.1)	548 (16.6)	2013 (64.4)	2173 (65.3)	421 (13.5)	401 (12.0)	511 (16.4)	588 (17.7)
S. Tyneside	1469	1448	1490	1467	21 (1.4)	19 (1.3)	62 (4.2)	54 (3.7)	324 (21.7)	368 (25.4)	986 (66.2)	945 (64.4)	171 (11.5)	178 (12.1)	312 (20.9)	326 (22.2)
Gateshead	1744	1649	1769	1682	25 (1.4)	29 (1.8)	62 (3.5)	62 (3.7)	378 (21.4)	368 (22.3)	1092 (61.7)	1069 (63.6)	238 (13.5)	211 (12.5)	348 (19.7)	358 (21.3)
Newcastle RVI	4816	5089	4913	5176	89 (1.8)	87 (1.7)	112 (2.3)	194 (3.7)	1041 (21.2)	808 (15.9)	2922 (59.5)	3200 (61.8)	851 (17.3)	763 (14.7)	1140 (23.2)	1019 (19.7)
N. Tyneside	1742	1740	1763	1762	21 (1.2)	22 (1.3)	59 (3.3)	72 (4.1)	291 (16.5)	323 (18.6)	1376 (78.0)	1308 (74.2)	104 (5.9)	97 (5.5)	254 (14.4)	330 (18.7)
Wansbeck	1865	1906	1891	1934	26 (1.4)	28 (1.5)	59 (3.1)	80 (4.1)	348 (18.4)	350 (18.4)	1136 (60.1)	1131 (58.5)	233 (12.3)	322 (16.6)	497 (26.3)	449 (23.2)
Berwick	23	20	23	20	0	0	0	0	0	0	23 (100)	20	0	0	0	0
Alnwick	40	62	40	62	0	0	0	0	0	0	40 (100)	62	0	0	0	0
Hexham	325	286	325	286	0	1 (0.3)	13 (4.0)	11 (3.8)	0	0	254 (78.2)	219 (76.6)	0	1 (0.3)	71 (21.8)	64 (22.4)
Cumberland Infirmary, Carlisle	1736	1714	1750	1735	14 (0.8)	21 (1.2)	69 (3.9)	57 (3.3)	277 (15.8)	314 (18.3)	1291 (73.8)	1220 (70.3)	124 (7.1)	168 (9.7)	319 (18.2)	318 (18.3)
W. Cumberland Infirmary	1252	1262	1267	1282	15 (1.2)	8 (0.6)	51 (4.0)	44 (3.4)	266 (21.0)	207 (16.4)	858 (67.7)	840 (65.5)	127 (10.0)	138 (10.8)	267 (21.1)	284 (22.2)
Penrith	52	62	52	62	0	0	0	0	0	0	52 (100)	62 (100)	0	0	0	0
Total	30735		31167		423		1041		6377		20685		3552		6290	

* Bishop Auckland Hospital became a midwifery led unit on 10 May 04; ** "Twins" is the number of women who delivered twins.

8. MATERNAL MORBIDITY

Introduction

This chapter provides an update on two aspects of maternal morbidity:

- An update on the project with the National Patient Safety Agency (NPSA) to compare approaches to the investigation of "near misses";
- An update on maternal obesity.

NPSA Project

In January 2006, we finally came on stream with this project, a collaboration with, and funded by, the National Patient Safety Agency. The project midwife was appointed and clerical support is provided from within the RMSO.

The purpose of the project is to audit the effectiveness of two tools, Root Cause Analysis (RCA) and Anonymised Case Review (ACR, better known as Confidential Enquiry), in ascertaining the underlying causes of serious adverse events in obstetrics. The reason for doing this is that the NPSA has been promoting the use of RCA as an aid to better understanding the underlying reasons for adverse events, based on models used in other safety-critical enviroments and industries; at the same time, the Confidential Enquiries (such as CEMACH) are also now under its administration, and these have developed various models of confidential enquiry. Yet the underlying rationale and purpose is the same for both: the need to prevent recurrences through systems analysis, individual learning, and organisational change. It is therefore important and pertinent to ascertain how each of these rather different techniques performs: what are their strong and weak points, and do they produce different perspectives on cases?

The adverse events that we are using are serious obstetric haemorrhage and obstetric thrombo-embolic events. The design has a retrospective phase and a prospective phase. The retrospective cases are ascertained from the regional obstetric morbidity survey database that ran from 1998 to 2002 in the Northern Region. These cases will be subject to both RCA and ACR panels, the notes being anonymised in all instances. The prospective cases will be ascertained from actual events occurring in the maternity service at the Royal Victoria Infirmary, Newcastle upon Tyne. These will be subject to formal case reviews in the normal way, with RCA; and the cases will subsequently be anonymised and subjected to the scrutiny of an ACR (i.e. confidential enquiry) panel. We hypothesise that scrutiny of retrospective cases will produce broadly similar results, irrespective of whether RCA or ACR is used; whereas we anticipate that RCA may produce quite different results to ACR for the prospective ones.

An initial pilot of feasibility was held in the late summer of 2005 and the results presented to the NPSA at the external reference group meeting on 23 September 2005. The current status of the project is that a series of RCA and ACR panels have been held, using anonymised retrospective cases. These should complete in early 2007.

We have:

- Developed and piloted a proforma, derived from existing confidential enquiry proformas, suitable for this type of ACR;

- Devised a semi-structured short telephone interview proforma for use with panel participants, to evaluate their experiences and ascertain their perceptions of the educational value of the panel meeting;
- Developed a project plan for the rest of 2006 to cover the retrospective phase of the project;
- Engaged a pool of clinicians – midwives, obstetricians, haematologists, and obstetric anaesthetists – who are happy to participate in panels.

We are always on the lookout for more midwives, obstetricians, haematologists, and obstetric anaesthetists who might be interested in participating in the panels. They attract continuing professional development (CPD) points, and our experience with panels over many years is that once people have participated, they can't wait for the chance to do another. However we also realise that time is precious, and for that reason the larger the pool of interested parties, the better. We are keeping to half-day sessions as it is much more difficult for participating clinicians to free up a whole day. So if you would like to join a panel, please contact Sharon Chilton or Martin Ward Platt through the RMSO.

Maternal obesity

Obesity continues to be a major public health issue. Obesity in pregnancy is associated with adverse perinatal outcomes for both the mother and infant. Around 20% of women of childbearing age are obese (BMI >30) and 30% overweight and the prevalence of obesity among women of childbearing age (16-44 years) in the UK is increasing. Regional variations in the prevalence of obesity have been demonstrated, with the North East of England having the highest regional prevalence.[16]

There is an absence of national, regional and local statistics on the population prevalence of maternal obesity in the UK. The RMSO collects information on maternal weight and height (and hence BMI) in all of its surveys but it was unclear whether this information is available for all births. A scoping study to assess both the level of data currently routinely collected in the regional maternity units and how accessible these data are, was commissioned by NEPHO in 2005 and completed in July 2006. The full report is available at the NEPHO website. The main findings are summarised below:

- Data collection systems allowing us to gain understanding of maternal obesity vary across the region, with data currently being collected, collated and stored in different ways.
- There are consistent concerns from staff relating to maternal obesity throughout the region, which cover the whole spectrum of care in pregnancy.
- There is a lack of consistency in services in the region for obese women in pregnancy.
- There is lack of evidence on which to base clinical policy.
- Health care professionals in the region consider maternal obesity has a major impact on practice.
- Health care professionals find communicating appropriate health advice to obese pregnant women difficult.

In 2007 the RMSO and Newcastle University will carry out data linkages between hospital data and data held on the RMSO surveys to examine the contribution of maternal obesity to a number of adverse pregnancy outcomes.

[16] DEPARTMENT OF HEALTH (2002a) *Health Survey for England 2002: Health and lifestyle indicators for Strategic Health Authorities, 1994- 2002,* London: HMSO.

9. NORTHERN MULTIPLE PREGNANCY REGISTER

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 3340 twin pregnancies, 98 triplet pregnancies and seven higher order multiple pregnancies have been notified to the MPR during the eight years, 1998-2005. Table 9.1 shows the number of multiple pregnancies and twinning rates by year. The twinning rate apparently peaked in 2002 at 16.6 per 1000 maternities but has decreased since then. These twinning rates compare with the rates of 9.8 per 1000 maternities in 1990 and 12.0 in 1994.[17]

Table 9.1. Numbers of multiple pregnancies and twinning rates, 1998-2005

	1998	1999	2000	2001	2002	2003	2004	2005
Twin pregnancies	478	448	461	432	490	480	493	508
Twin maternities*	432	417	424	413	479	458	445	471
Triplet pregnancies	17	22	15	10	11	12	5	6
Higher order multiple pregnancies	2	1	1	2	0	1	0	0
TWINNING RATE / 1,000 maternities	13.6	13.6	14.5	14.4	16.6	15.3	14.3	14.9
Total maternities	31737	30652	29331	28718	28895	29849	31202	31611

* 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. Although several papers have been written using the data and others are planned, as a resource this register is not being used to its full potential.

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 liveborn twins, this has not been the case when the pregnancy has resulted in other outcomes. Cases can not be put onto the MPR until consent is received. This means that currently case ascertainment is not complete.

At a meeting of the Steering Group (see Appendix 6 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.

To this end, a half-day meeting is planned for April 2007 to showcase what clinical issues can be addressed using data from the MPR. This meeting will include a session during which the Steering Group will engage with clinicians to discuss how the register can enhance the provision and organisation of care for women with multiple pregnancies – for example, by using the register to audit outcomes in women with multiple pregnancies. 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.

Further, an application will be made in 2007 to the Patient Information and Advisory Group (PIAG) for Section 60 approval to process data on early losses.

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

[17] GLINIANAIA 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.

10. NORTHERN CONGENITAL ABNORMALITY SURVEY (NORCAS)

Background

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

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

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

Table 10.1 reports the number and total prevalence rate per 10,000 registered births for selected congenital anomalies by year for the five years 2000-2004.

Register Developments

EUROCAT

NorCAS is a full member of the European Surveillance of Congenital Anomalies (EUROCAT), a network of European congenital anomaly registers from 31 countries.[18] NorCAS has now contributed five years of data (2000-2004). NorCAS is currently involved in the following EUROCAT projects;

- Epidemiology of selected rare syndromes in Europe;
- Prevalence and surveillance of sentinel phenotypes in Europe;
- Twin study: ischaemic 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.

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

Table 10.1 Number and total prevalence rate for selected congenital anomalies notified to NorCAS, 2000-2004*#.

* Number of cases occurring in livebirths, stillbirths, miscarriages after 20 weeks gestation and termination of pregnancy for fetal anomaly

#Anomaly subgroups based on those most recently published by EUROCAT, available at http://www.eurocat.ulster.ac.uk/pdf/EUROCAT-Guide-1.3.pdf. These were published in 2005 and will account for differences in numbers to those published in previous reports

Anomaly Subgroup	2000		2001		2002		2003		2004		Total	
	No.	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*	*No.*	*Rate*
Nervous system	**75**	**25.2**	**87**	**29.9**	**79**	**26.9**	**88**	**29.0**	**63**	**20.2**	**392**	**26.2**
Neural tube defects	43	14.4	43	14.8	35	11.9	50	16.5	36	11.5	207	13.8
Anencephaly	21	7.1	16	5.5	12	4.1	23	7.6	15	4.8	87	5.8
Encephalocele	4	1.3	2	0.7	3	1.0	5	1.7	1	0.3	15	1.0
Spina bifida	18	6.0	25	8.6	20	6.8	22	7.3	20	6.4	105	7.0
Hydrocephaly	17	5.7	18	6.2	17	5.8	19	6.3	8	2.6	79	5.3
											0	
Eye	**19**	**6.4**	**12**	**4.1**	**7**	**2.4**	**9**	**3.0**	**11**	**3.5**	**58**	**3.9**
Ear, face and neck	**3**	**1.0**	**1**	**0.3**	**4**	**1.4**	**3**	**1.0**	**3**	**1.0**	**14**	**0.9**
Congenital heart disease	**310**	**104.1**	**255**	**87.8**	**326**	**110.9**	**364**	**120.0**	**276**	**88.5**	**1531**	**102.2**
Common arterial truncus	3	1.0	2	0.7	4	1.4	6	2.0	1	0.3	16	1.1
Transposition of great arteries	14	4.7	14	4.8	8	2.7	17	5.6	17	5.5	70	4.7
Ventricular septal defect	169	56.7	141	48.5	151	51.4	176	58.0	118	37.8	755	50.4
Atrial septal defect	40	13.4	49	16.9	80	27.2	79	26.1	65	20.8	313	20.9
Atrioventricular septal defect	17	5.7	18	6.2	17	5.8	23	7.6	22	7.1	97	6.5
Tetralogy of Fallot	26	8.7	12	4.1	22	7.5	16	5.3	16	5.1	92	6.1
Tricuspid atresia and stenosis	4	1.3	0	0.0	1	0.3	3	1.0	4	1.3	12	0.8
Pulmonary valve stenosis	28	9.4	21	7.2	46	15.7	41	13.5	38	12.2	174	11.6
Aortic valve atresia/stenosis	9	3.0	9	3.1	10	3.4	11	3.6	4	1.3	43	2.9
Hypoplastic left heart	5	1.7	7	2.4	6	2.0	5	1.7	8	2.6	31	2.1
Coarctation of aorta	16	5.4	17	5.9	16	5.4	14	4.6	22	7.1	85	5.7
Oro-facial clefts	**47**	**15.8**	**48**	**16.5**	**47**	**16.0**	**65**	**21.4**	**50**	**16.0**	**257**	**17.2**
Cleft lip with or without palate	28	9.4	32	11.0	29	9.9	35	11.5	30	9.6	154	10.3
Cleft palate	19	6.4	16	5.5	18	6.1	30	9.9	20	6.4	103	6.9

Anomaly Subgroup	2000		2001		2002		2003		2004		Total	
Digestive system**	**55**	**18.5**	**44**	**15.1**	**40**	**13.6**	**43**	**14.2**	**33**	**10.6**	**215**	**14.4**
Oesophageal atresia with or without fistula	16	5.4	9	3.1	8	2.7	7	2.3	4	1.3	44	2.9
Duodenal atresia or stenosis	7	2.4	5	1.7	11	3.7	5	1.7	6	1.9	34	2.3
Ano-rectal atresia and stenosis	10	3.4	12	4.1	9	3.1	10	3.3	9	2.9	50	3.3
Diaphragmatic hernia	18	6.0	14	4.8	15	5.1	9	3.0	9	2.9	65	4.3
											0	
Urinary	**104**	**34.9**	**111**	**38.2**	**78**	**26.5**	**103**	**34.0**	**99**	**31.7**	**495**	**33.1**
Bilateral renal agenesis	9	3.0	7	2.4	3	1.0	10	3.3	6	1.9	35	2.3
Cystic kidney disease	24	8.1	17	5.9	15	5.1	25	8.2	25	8.0	106	7.1
Congenital hydronephrosis	34	11.4	42	14.5	22	7.5	35	11.5	22	7.1	155	10.3
Limb	**31**	**10.4**	**29**	**10.0**	**36**	**12.3**	**39**	**12.9**	**32**	**10.3**	**167**	**11.2**
Upper limb reduction	11	3.7	8	2.8	11	3.7	12	4.0	13	4.2	55	3.7
Lower limb reduction	4	1.3	9	3.1	3	1.0	4	1.3	5	1.6	25	1.7
Abdominal wall defects	**17**	**5.7**	**20**	**6.9**	**24**	**8.2**	**33**	**10.9**	**35**	**11.2**	**129**	**8.6**
Gastroschisis	9	3.0	11	3.8	8	2.7	20	6.6	23	7.4	71	4.7
Exomphalos	7	2.4	9	3.1	14	4.8	10	3.3	12	3.9	52	3.5
Chromosomal	**123**	**41.3**	**138**	**47.5**	**127**	**43.2**	**121**	**39.9**	**142**	**45.5**	**651**	**43.5**
Down's syndrome	59	19.8	63	21.7	74	25.2	58	19.1	84	26.9	338	22.6
Patau syndrome (trisomy 13)	4	1.3	7	2.4	3	1.0	9	3.0	8	2.6	31	2.1
Edward's syndrome (trisomy 18)	14	4.7	11	3.8	9	3.1	22	7.3	22	7.1	78	5.2
Turner's syndrome	7	2.4	14	4.8	7	2.4	8	2.6	5	1.6	41	2.7
Klinefelter's syndrome	2	0.7	3	1.0	2	0.7	3	1.0	2	0.6	12	0.8
All cases	**757**	**254.2**	**719**	**247.4**	**724**	**246.3**	**772**	**254.5**	**698**	**223.7**	**3670**	**245.0**
Total no. of births	**29785**		**29060**		**29394**		**30329**		**31202**		**149770**	

**Numbers expected to change due to ongoing cross-validation with the Information Services at the RVI

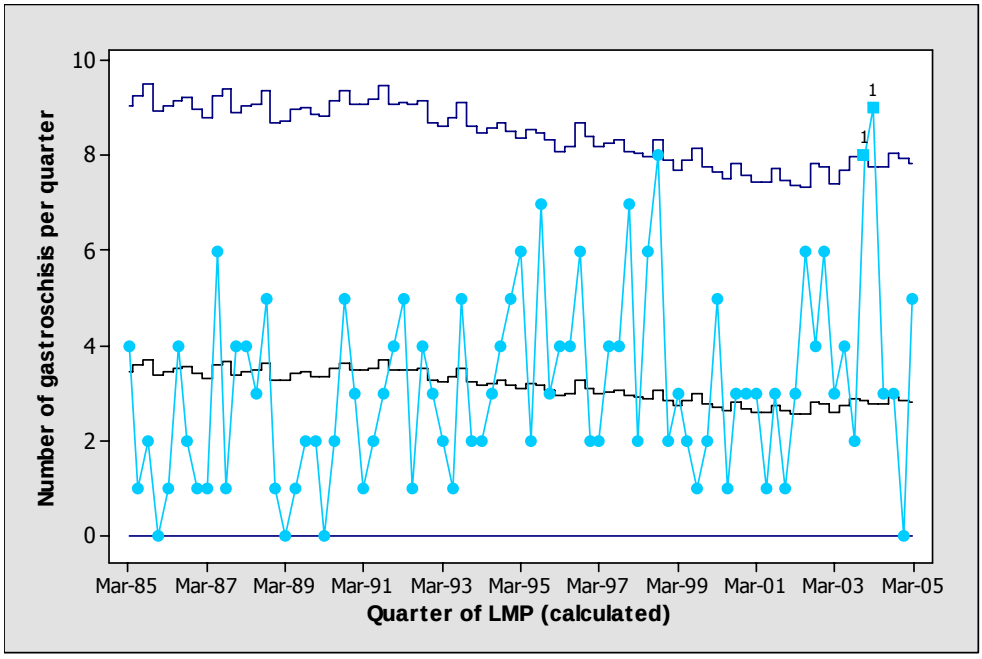
NorCAS continues to be an active member of the British Isles Network of Congenital Anomaly Registers (BINOCAR).[19]

Routine Surveillance

Routine surveillance of EUROCAT data is undertaken regularly and we were asked to respond to a list of potential trends and clusters in our data that were detected using EUROCAT surveillance procedures on the five years of data now submitted from NorCAS. Extensive reports were created for EUROCAT and the NorCAS Steering Group addressed each potential trend and cluster. We were able to look at a much longer period of time, which put the EUROCAT trends into perspective. Overall, trends could be explained by changes in reporting or ameliorated by looking at the longer term. In most cases, provisional 2005 rates are expected to break the apparent recent trends.

An apparent temporal cluster of gastroschisis in the region in the early part of 2004 was identified and still remained significant when the full twenty years of data was analysed. There is no apparent geographic component to this cluster. Enhanced pro formas were sent out to units for each case occurring within the cluster to ascertain potential exposure risks, but these show no obvious additional factors for investigation. Other registers in the BINOCAR network report no clusters of gastroschisis at the same time interval.

Figure 10.1: Control chart monitoring the quarterly occurrence of gastroschisis based on (calculated) LMP 1985 to March 2005. Note the two quarters (Dec 2003 and Mar 2004) that fall outside of the three standard deviation control limits.



The process in responding to the surveillance report highlighted some problems with coding, interpretation of diagnostic information and reporting deficiencies. In response, we are now carrying out more cross-validation with hospital information service departments. We have also refined coding criteria for some anomalies and are pursuing areas of deficient reporting. Routine monitoring on selected anomalies was also carried out in house.

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

The gastroschisis clusters were confirmed during this process (see Figure 10.1). No other recent temporal clusters were picked up during this analysis.

The RMSO continues to respond to cluster alerts sent to Directors of Public Health by NCAS.

Links with the Human Fertilisation & Embryology Authority (HFEA)

This project has received approval from the Patient Information Advisory Group (PIAG) and MREC. Now that all the research governance is in place, this feasibility study can move forward.

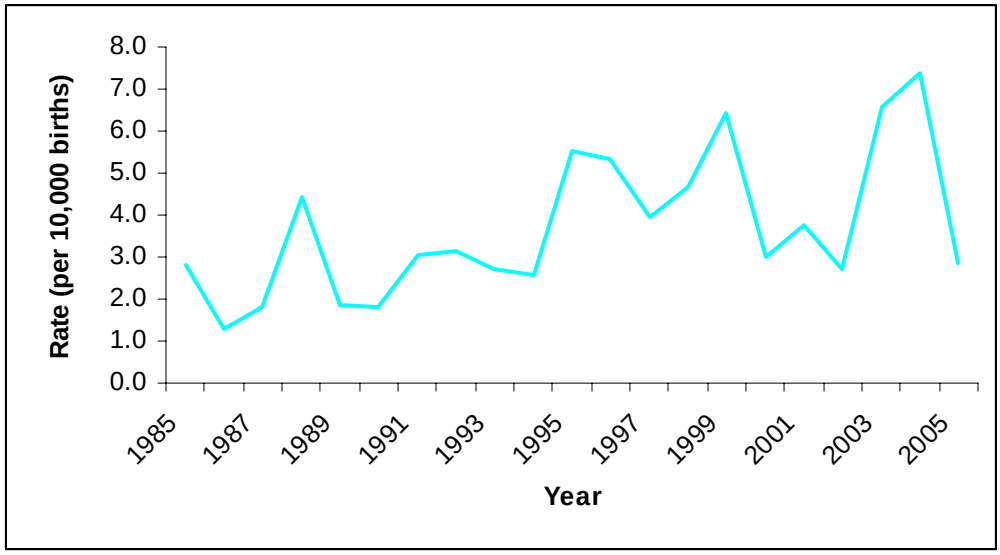
Down's Syndrome Screening Programme Audit

The National Screening Committee (NSC) standards recommend that overall audit and monitoring of antenatal screening programmes should be performance managed at Strategic Health Authority (SHA) level or regional level.[20] The first year of data collection is now complete and has been submitted to the Regional Antenatal Screening Co-ordinator. A report will be prepared for the NSC.

Gastroschisis

An increase in the prevalence of gastroschisis has been observed regionally, nationally and internationally. Figure 10.2 shows the year on year fluctuation in prevalence of gastroschisis in the Northern Region. The increase in prevalence rate which began again in 2003 (6.9 per 10,000 births) and 2004 (7.7 per 10,000) has decreased to 2.9 per 10,000 births in 2005. Continued monitoring of the prevalence of gastroschisis is necessary to know whether this decrease continues or not.

Figure 10.2: Secular change in total prevalence of gastroschisis in the Northern Region, 1986-2005.



[20] DEPARTMENT OF HEALTH. Commissioning and managing screening programmes in England. At http://www.dh.gov.uk/assetRoot/04/11/86/00/04118600.pdf

Lifestyle factors

The 2006 Annual NorCAS meeting was held in the James Cook University Hospital in Middlesbrough (see Appendix 3 for the programme). It was very well attended and the feedback suggests that it was judged to be one of the best meetings to date! The theme of the afternoon was the contribution of maternal lifestyle factors to congenital anomaly risk. There is widespread concern that changes both in individual lifestyle (e.g. diet and use of tobacco, prescribed and illegal drugs, alcohol misuse), and in environmental exposures such as to endocrine disruptors and particulate air pollution, impact especially on the health of children reflecting their unique vulnerability. The topics covered during the day were:

1. the contribution of assisted reproductive technologies to the occurrence of congenital anomalies;
2. the results of a systematic review of the effects of low to moderate exposure to alcohol in pregnancy;
3. a review of a specialised clinic for pregnant women who are substance users;
4. an overview of existing studies of maternal obesity and congenital anomalies and the introduction to a study using NorCAS data to assess the contribution of maternal obesity to congenital anomaly risk (see below).

The contribution of these factors to pregnancy outcome is difficult to assess. Population based data such as that held by NorCAS play an essential role in providing the means to address these important societal concerns. There are a number of research projects underway and planned to further assess the contribution of these factors to the occurrence of congenital anomalies.

Research

Ongoing projects

Antenatal renal anomalies – a new way of service delivery

Antenatal detection of renal anomalies is common; reported in 1-3% of routine scans. Clinical impression and previous audit within the RVI have shown that babies identified with antenatal renal anomalies were not always receiving appropriate follow up – some were being lost in the system, others over-investigated. Information given to families was variable. We have reviewed existing protocols in the light of current evidence and produced unified antenatal and postnatal guidelines for common conditions. A new system of service delivery was introduced in January 2006 in which an antenatal renal co-ordinator takes responsibility for the investigation of these babies. She counsels the families antenatally and postnatally, provides written information, performs the 34 week scan, and the first (and second) post natal ultrasound scans in the obstetric department. She initiates further imaging investigations in radiology and medical physics and provides information on scan results, management plans and follow up to the GP, health visitor, medical professionals and the family. Detailed data is collected on these babies with a view to long term audit and review of clinical outcomes to aid future revision of guidelines.

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 will involve data on all women who booked in one of five maternity units in the Northern region during 2002-05, and data from NorCAS. The relationship between maternal obesity at booking and the prevalence of congenital anomalies (total and birth prevalence) will be investigated, allowing for relevant covariates including maternal age, smoking, socio-economic status, folic acid use. If an association

between maternal obesity and the occurrence of congenital anomalies is demonstrated, this will provide the basis for a programme of prospective work in this field.

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 will ascertain 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.

Recreational drug use: a risk factor for gastroschisis?

Recent studies have demonstrated a 2-3 fold rise in the birth prevalence of gastroschisis without a corresponding increase in the prevalence of exomphalos. [21] Current aetiological hypotheses suggest that this increase may result from maternal exposures, specifically, a link between recreational drug use and gastroschisis has been postulated. This case control study is measuring any excess risk of gastroschisis associated with recreational drug use.

[21]RANKIN J, DILLON E, WRIGHT C. Congenital abdominal wall defects in the Northern Region, 1986-95: occurrence and outcome. *Prenatal Diagnosis* 1999;19:662-8.

Congenital anomalies and air pollution; the CAAP study

This study investigates whether maternal exposure to air pollutants is associated with an increased risk of birth defects in a cohort of infants and fetuses delivered in the Northern Region during 1985-90. To date, only one study has examined the risk of birth defects in relation to ambient air pollution. [22] Ritz and colleagues reported an increase in the risk of cardiac defects with carbon monoxide (CO) exposure; there were no relationships with other air pollutants. This study was limited to only a few birth defect types and the authors called for further research in different settings to verify these findings.

A study of the geographical variation in the overall rates of congenital abnormalities and the rates of specific abnormalities

The geographical variation in the distribution of congenital anomalies is being studied in an ongoing multicentre UK collaborative project involving five congenital anomaly registers (NorCAS, Glasgow, North Thames West, Wessex and Oxford). The project aims to understand the variation in risk of congenital anomalies in space and time, and will provide important clues to the role of environmental and other exposures in the aetiology of these conditions.

Small intestinal atresia in the Northern region; occurrence and antenatal diagnosis

Small intestinal atresia (SIA) is a serious congenital anomaly requiring surgery. It is thought to result from a disruption to the fetal mesenteric vasculature in early pregnancy. There have been few epidemiological studies of SIA, but it has been postulated that risk factors for gastroschisis, a congenital anterior abdominal wall defect, may be the same for SIA. Thus, smoking, recreational drugs and other vasoconstrictors may be risk factors for this anomaly. It has also been suggested that the prevalence of this anomaly may be increasing. This study will describe the prevalence, outcome, antenatal diagnosis and associated anomalies for this congenital anomaly subtype.

Is congenital abnormality a risk factor for childhood cancer?

There are several known links between congenital abnormality and childhood cancer, for example Down's syndrome and neurofibromatosis. Down's syndrome carries an increased risk of leukaemia, but appears to provide protection against solid tumours. There has been no previous population based investigation in the UK that links all incident cancer with all previously identified congenital abnormality. The project is a record-linkage geographical cohort study, from 1985-2001, using data from NorCAS and from the Northern Region Young Persons Malignant Disease Registry (NRYPMDR).

[22]RITZ B, YU F, FRUIN S, CHAPA G, SHAW GM, HARRIS JA. Ambient air pollution and risk of birth defects in Southern California. *American Journal of Epidemiology* 2002;155(1):17-25.

11. 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 1991 as a prospective cerebral palsy survey across all districts in the former Northern Regional Health Authority. 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. For some years, NECCPS has been housed at the RMSO and for the last three years has been formally under the umbrella of the RMSO.

The survey holds historical data on 780 children born between 1960 and 1990 in the Northumberland, Newcastle and North Tyneside districts. As of September 2006, data on a further 1103 children from the former Northern Region are held for 1991 births onwards. The data held about 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 also 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.

More information is available in successive annual reports available from the RMSO office. Occasional special reports are produced using NECCPS data, the most recent was specifically aimed at parents of children with cerebral palsy.

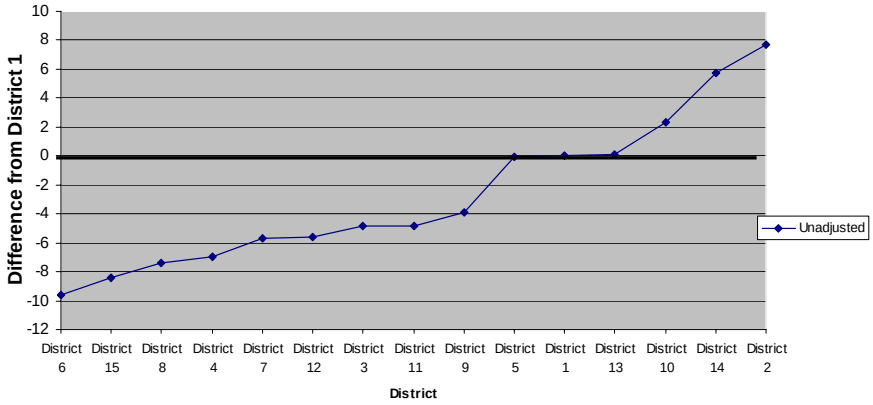
Participation

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

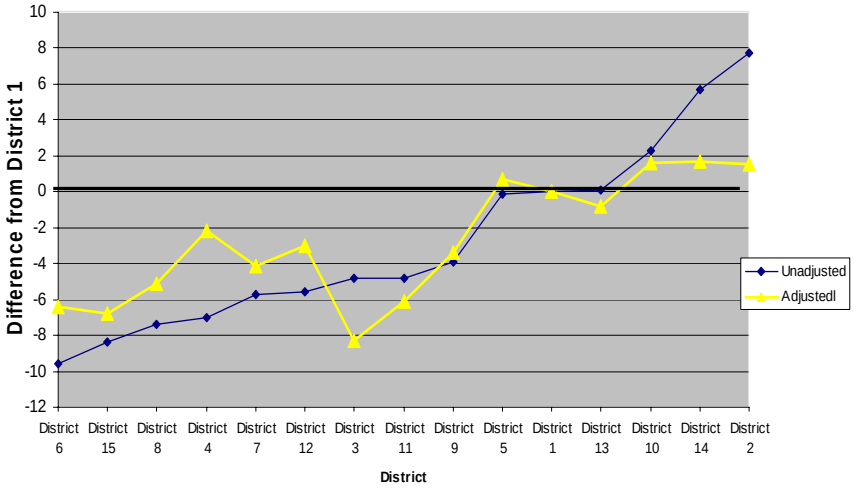
Below are two graphs from a recent publication.[23] The first shows that the participation of five year old children in the North of England varies with the district in which they live. The second graph shows that variation remains when the graph is adjusted to control for severity of cerebral palsy and social factors. The implication is that the environment is very important in determining participation. Newcastle now co-ordinates a European study which examines how participation varies in nine European centres and which features of the environment best promote participation.

[23] HAMMAL D, JARVIS SN, COLVER AF. *Participation of children with cerebral palsy is influenced by where they live.* Developmental Medicine and Child Neurology. 2004;46:292-298.

Mean LAS (participation restriction)



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



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

This study has been ongoing for four years and is nearly completed. Eight hundred and eighteen 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. The results will be published in academic journals and disseminated to parents, voluntary groups, public bodies and government. Below are some preliminary conclusions but we still have many more analyses to undertake and questions to ask.

QUALITY OF LIFE (as reported by the children themselves)
The measure of quality of life asked children to report how they viewed 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.

- 61% of the children could self report; the remaining 39% had learning difficulty which prevented them from being able to give a clear account.
- Quality of Life (QoL) on many dimensions is not determined by severity of impairment. Indeed, some children with mild CP have poorer quality of life.
- 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.

PAIN

- Children with CP have more pain than had been thought, including in particular children with milder CP.
- Children with CP have considerably more pain than the general population.
- Pain has a pervasive influence on reducing QoL.
- Pain only seems to be influenced by severity of impairment at the severest end of the spectrum.

PARENT VERSUS CHILD REPORT

- When comparing what the child says about their quality of life with what the parent says, the agreement was fairly low, with the child's quality of life usually reported as higher by the child than by their parents. It is quite reasonable that children and parents differ - they both report from their own perspective.

MENTAL HEALTH

- Mental health of children with CP is less good in the children with better motor function – a surprising and interesting result.
- Children with CP have less good mental health than the general population.
- Nearly a quarter of the children with cerebral palsy had problems with behaviour - most commonly problems with other children. The risk of behavioural difficulties increased with better walking ability, epilepsy, learning difficulty and pain. The risk was also increased for children without brothers or sisters, or with ill or disabled brothers and sisters. Most parents said the behavioural difficulties were quite a burden for the family.

PARTICIPATION

- Children with cerebral palsy do not "Participate" as much as non disabled children. "Participating" means joining in all the aspects of life we want all children to. Children with cerebral palsy participate less and the more severe their cerebral palsy, the less they participate.

Working with Parents

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

- The survey conducted a piece of qualitative work with 12 families to find out what kind of information parents want and need about such a survey.

- An information sheet is available about the survey.
- Permission from parents is now sought before their child's name is submitted to the survey. In the past, this permission was not sought until their child reached age 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.
- The programme of each annual meeting contains some talks specifically for parents. Forty parents attended the last meeting, of which two gave a presentation about a skiing trip to the US with their severely disabled children.
- A SCOPE grant of £1500 was received in 2005 to fund a family day out at the Discovery Museum in Newcastle. The event included an educational component for the parents, including sessions on raising self-esteem and on wheelchair and bicycle provision, whilst children toured the museum with carers or crèche workers. This was a great success with 70 children and parents attending at the Discovery Museum. There was an interest expressed by those attending for future events. These may be held in other parts of the region if funding can be obtained.
- Since 2004, three newsletters have gone out to all families outlining the purpose and activities of the Survey and other relevant regional and national information.
- The possibility of the provision of a moderated NECCPS website will be explored. General data are available on the NEPHO website.

2006 NECCPS Annual Meeting

The NECCPS Annual Meeting continues to be an effective forum for all professionals involved in the care of children with cerebral palsy. The increasing number of parents involved in the annual meeting enhances the relevance of this forum. This year, 150 people attended to hear a programme themed "Getting it Right in the Early Years and Beyond School Leaving". Some highlights of the day included a talk by a team from the Percy Hedley Academy for Disability Sports on the development of sporting opportunities for children with disability and a presentation by Dr Ruth Kent on future health care needs of young adults with cerebral palsy. Copies of some presentations are available on request from the RMSO.

Current data September 2006

The tables show data about children whose mothers were normally resident in the region at the time of delivery.

Table 11.1: 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**	**4**	**4**	**5**	**3**	**3**	**2**
Newcastle	10	9	13	5	6	9	9	6	2	6	1	0
North Tyneside	10	10	2	2	3	4	3	5	7	3	3	2
Newcastle & North Tyneside	**20**	**19**	**15**	**7**	**9**	**13**	**12**	**11**	**9**	**9**	**4**	**2**
Gateshead	9	8	4	5	2	6	7	2	6	7	0	4
South Tyneside	4	4	9	7	6	3	6	4	3	2	1	0
Gateshead & South Tyneside	**13**	**12**	**13**	**12**	**8**	**9**	**13**	**6**	**9**	**9**	**1**	**4**
Sunderland	**5**	**14**	**10**	**17**	**10**	**8**	**13**	**7**	**11**	**7**	**3**	**6**
North Tees	7	6	8	8	9	7	15	11	6	2	1	2
South Tees	14	13	14	8	15	14	8	8	7	8	8	2
Hartlepool	2	2	6	9	3	2	7	8	4	2	2	2
Tees	**23**	**21**	**28**	**25**	**27**	**23**	**30**	**27**	**17**	**12**	**11**	**6**
N.W. Durham	4	0	2	0	3	6	4	2	4	3	1	2
Durham	4	4	6	4	2	2	7	5	1	4	1	1
S.W. Durham	8	12	6	4	5	7	7	6	5	3	4	11
Darlington	3	3	6	4	1	5	5	1	2	2	2	6
Co. Durham	**19**	**19**	**20**	**12**	**11**	**20**	**23**	**14**	**12**	**12**	**8**	**20**
W. Cumbria	4	2	2	2	3	5	6	8	1	3	0	0
E. Cumbria	6	1	4	7	4	7	5	2	5	5	5	2
North Cumbria	**10**	**3**	**6**	**9**	**7**	**12**	**11**	**10**	**6**	**8**	**5**	**2**
North of England Excluding S. Cumbria	**99**	**101**	**96**	**89**	**79**	**96**	**106**	**79**	**69**	**60**	**35**	**42**

Table 11.2: Registration rates by former health "districts"

District or area	Three year rolling registration rate per 1,000 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**	**2.26**	**1.97**	**1.38**
Newcastle	2.96	2.57	2.33	1.99	2.45	2.53	
North Tyneside	3.05	2.03	1.04	1.37	1.53	2.01	
Newcastle & North Tyneside	**3.00**	**2.35**	**1.82**	**1.75**	**2.08**	**2.26**	**2.08**
Gateshead	2.88	2.44	1.66	1.84	2.29	2.35	
South Tyneside	2.81	3.43	3.88	2.92	2.79	2.52	
Gateshead & South Tyneside	**2.85**	**2.88**	**2.64**	**2.31**	**2.51**	**2.42**	**2.40**
Sunderland	**2.50**	**3.68**	**3.41**	**3.32**	**3.02**	**2.81**	**3.22**
North Tees	2.80	3.08	3.65	3.63	4.79	5.12	
South Tees	3.20	2.72	3.08	3.19	3.40	2.84	
Hartlepool	2.57	4.49	4.77	3.86	3.44	5.18	
Tees	**2.98**	**3.13**	**3.54**	**3.48**	**3.84**	**3.94**	**3.75**
N.W. Durham	1.85	0.64	1.64	3.09	4.49	4.22	
Durham	1.54	1.60	1.44	0.98	1.11	1.25	
S.W. Durham	4.36	3.84	2.75	3.00	3.65	3.70	
Darlington	2.47	2.76	2.40	2.21	2.34	2.36	
Co. Durham	**2.51**	**2.29**	**2.01**	**2.06**	**2.62**	**2.80**	**2.46**
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**	**1.59**	**1.94**	**2.64**	**2.87**	**3.19**	**2.71**
North of England (excludes South Cumbria)	**2.60**	**2.59**	**2.47**	**2.56**	**2.79**	**2.85**	**2.65**

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- LAWLOR K, WELSH B, MIHAYLOV SI, JARVIS S, COLVER AF. *Qualitative study of physical, social and attitudinal environment for children with cerebral palsy*. In press Pediatric Rehabilitation
- WELSH B, JARVIS S, HAMMAL D, COLVER AF. *How might districts identify local barriers to participation for children with cerebral palsy*? Public Health 2006:120(2):167-75
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APPENDIX 1 RMSO ADVISORY GROUP MEMBERSHIP

(2005/06)

Dr Joan Arvold	Programme Director
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Dr Tricia Cresswell	Director RMSO/Director of Public Health
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Dr Chris Wright	Consultant Perinatal Pathologist

APPENDIX 2 PUBLICATIONS INVOLVING RMSO DATA

(excluding NECCPS – see pages 56-7)

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APPENDIX 3 PROGRAMMES FOR ANNUAL MEETINGS 2006

- PMMS Annual Meeting 17 March 2006
- NECCPS Annual Meeting 22 March 2006
- Northern Diabetes in Pregnancy Survey Summer Workshop 4 July 2006
- NorCAS Annual Meeting 20 October 2006

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R M S O
REGIONAL MATERNITY SURVEY OFFICE

Perinatal and Maternal Mortality Survey
Annual Meeting
Freeman Hospital, Newcastle upon Tyne, 17 March 2006

Celebrating 25 Years of the Survey

NEW PROBLEMS

09.00	**Coffee and registration**	
09.30	Welcome and outline of the day	Rev Bryan Vernon (Chair)
09.40	1981 to 2006, problems then and now	Dr Edmund Hey Mr John Davison Dr Chris Wright
10.40	Panel Discussion	
11.00	**Coffee**	
11.30	Emotion versus reality – the problems of service reconfiguration	Mr David Evans
12.00	MOSAIC – a study of obstetric and neonatal outcomes for babies under 32 weeks	Dr David Milligan Dr Alan Fenton Mr Steve Sturgiss
12.40	**Lunch**	
13.30	Update on PMMS and CEMACH	Dr Tricia Cresswell
14.00	Update on maternal obesity	Ms Kath Mannion Ms Nicola Heslehurst
14.30	The problem in older mothers? • Rising maternal age: an epidemiological perspective • Assisted conception and obstetric outcomes	 Dr Ruth Bell Mrs Cath Emmerson
15.30	Panel discussion	
16.00	**Close**	

Eleventh Conference and Annual Meeting
NORTH OF ENGLAND COLLABORATIVE CEREBRAL PALSY SURVEY
Wednesday, 22nd March 2006 – 10am-4pm
Menzies Hotel, Silverlink, North Tyneside

Cerebral Palsy –
Getting it Right in the Early Years and Beyond School Leaving

Morning session

9.30 Coffee and registration

10.00 Chair: Rosemary Menzies, Consultant Paediatrician,
Queen Elizabeth Hospital, Gateshead

10.05 Right from the start – Are we improving the way in which news of a child's additional needs is shared with parents?
Janet Lees, Early Years Co-ordinator, SCOPE

10.35 Implementing "Right from the start" in Gateshead
Kath Ingleby, Specialist Health Visitor, Gateshead PCT
Anne Pointer, Preschool Teacher
Janice Nye, Community Midwife

10.55 The challenge of the ski slopes
Lesley Moore and Janet Cummings, Parents

11.10 **Coffee**

11.35 Future health care needs of young adults with cerebral palsy
Ruth Kent, Consultant and Senior Lecturer in Neurological Rehabilitation, Yorkshire

12.25 The role of Connexions for teenagers at the time of transition
Olivia Slingsby, Connexions Advisor, Sunderland

1:05 Lunch

Afternoon session

2.05 Chair: Mary Gibson, Consultant Paediatrician, Child Development Centre, RVI

2.10 A sporting chance in the North East
Stewart Evans, Head Occupational Therapist, Percy Hedley Schools
Stephen Miller, Paralympic Gold Medallist
Adam Parry, Sports Development Manager, Percy Hedley

2.45 SPARCLE update
Allan Colver, Consultant Paediatrician and NECCPS Chair, and Colleagues

3.20 Ataxic cerebral palsy – Are we getting it right?
Dr Sethu Wariyar, Consultant Community Child Health, Great Ormond Street Hospital

3.40 Changes in impairment severity between the ages of 5 and 10 – A study using NECCPS and SPARCLE data
Sangeeta Joshi, Specialist Registrar in Paediatrics, Northumbria Healthcare NHS Trust

3.55 Close

R M S O

REGIONAL MATERNITY SURVEY OFFICE

Northern Diabetes in Pregnancy Survey
Summer Workshop

Gestational Diabetes Again!

Tuesday 4 July 2006, 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	Gestational Diabetes : ACHOIS	Dr Bob Fraser
14.05	Developing standards of care for gestational diabetes	Dr Rudy Bilous Dr Ruth Bell
14.50	Discussion	
15.10	**Tea**	
15.30	Developing a standardised baby feeding chart	Clare Patton
15.40	Attitudes to Pregnancy Risk and Conception among Women with Type 1 Diabetes	Dr Janice McLaughlin/ Dr Alison Hosie
16.10	Care of women with pre-gestational diabetes at Wansbeck and North Tyneside	Dr Nick Lewis-Barned
16.25	Pregnancy and Diabetes in Newcastle 1985-2005: Management and Outcomes	Prof Roy Taylor
17.00	**End**	

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NORTH EAST PUBLIC HEALTH OBSERVATORY

NorCAS Annual Meeting 2006

Friday 20th October 2006 – The Education Centre, James Cook University Hospital

Chair: **Mr Ian Willetts, Consultant Paediatric Surgeon, Royal Victoria Infirmary**

09.30 Coffee and registration

10.00 Introduction to the day

10.05 Antenatal renal anomalies – a new way of service delivery
Dr Heather Lambert, Consultant Nephrologist &
Diane Wheeler, Senior Sonographer, RVI

10.20 Congenital renal fusion
Mr John Scott, Retired Paediatric Surgeon, RMSO

10.35 Update on in utero interventions
Dr Stephen Sturgiss, Consultant in Fetal Medicine, Royal Victoria Infirmary

11.05 Postmortem audit of antenatal findings in terminations for congenital anomalies
Dr Chris Wright, Consultant Perinatal Pathologist, Royal Victoria Infirmary

11.25 Coffee

11.45 Update on assisted reproduction – technology and service delivery
Dr Jane Stewart, Consultant in Reproductive Medicine, Newcastle Fertility Centre

12.15 Assisted conception & congenital anomalies
Dr Jenny Kurinczuk, Consultant Clinical Epidemiologist,
National Perinatal Epidemiology Unit, Oxford

13.00 Lunch

Theme: **Lifestyle risk factors and congenital anomalies**
Chair: ***Professor John Wilkinson, Director NEPHO***

14.00 Systematic review of the effects of low-moderate prenatal alcohol exposure and binge drinking
Dr Ron Gray, Consultant Clinical Epidemiologist,
National Perinatal Epidemiology Unit, Oxford

14.30 Teratogens
Dr Simon Thomas, Reader in Therapeutics, Wolfson Unit of Clinical Pharmacology, Univ of Newcastle

14.50 Substance misuse: Four years on, what have we learned?
Dr Paul Moran, Consultant in Fetal Medicine, Royal Victoria Infirmary

15.10 Maternal obesity update
Dr Judith Rankin, Principal Research Associate, Newcastle University

15.30 Panel discussion – Lifestyle Risk Factors

16.00 Close

APPENDIX 4 NUMBERS OF BIRTHS 1991-2005 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

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 5 REGIONAL PRINCIPLES FOR UNDERTAKING INVESTIGATIONS OF SUDDEN UNEXPECTED DEATHS IN INFANCY

Authored by Dr Martin Ward Platt, consultant paediatrician and Clinical Director of the Regional Maternity Survey Office, on behalf of the Kennedy Report Recommendations Working Group

1. Scope

These principles are overarching and provide a framework for local operational guidelines but do not otherwise affect them. They are not exhaustive: they are simply those that are at variance with the Kennedy recommendations.

The principles listed here are designed in recognition that certain recommendations of the Kennedy report are aspirational rather than practical, and that if we are to implement arrangements at variance with the letter of the Kennedy report, it is important that we do this consistently and with regional agreement. The rationale for each statement is given in italics.

2. Initial information gathering

2.1. As much clinical and background history as possible will be gathered when the child is brought in dead, or being (unsuccessfully) resuscitated, in the A&E department.
This recognises the practicalities of making contact with the families, and is linked with 2.4 below.

2.2. It is ideal, though sometimes impractical, to take a clinical history from each parent or carer separately.
This recognises that clinical consultations, the recording of which may have relevance in the minority of cases where a forensic component subsequently comes to light, have greatest evidential value if it is possible to establish the pattern of consistency and inconsistency in the accounts of the carers.

2.3. Contact with Social Services should take place as soon as possible.
This is not just about child protection or the checking of the register: there may be issues relating to the welfare and safeguarding of other children in the household.

2.4. The needs and status of a police interview and a clinical consultation are different. Doctors and police should not, under normal circumstances, undertake joint interviews.
The rationale for this is that professional medical judgements can only be made in the context of a clinical consultation undertaken in a standard professional context, and that it would not be possible to undertake such a consultation under police caution. Similarly, a police interview would not be admissible unless it had been undertaken in the proper fashion. Therefore these processes must be kept separate.

2.5. Police information gathering will be undertaken, as far as resources allow, by officers with training in child protection, in accordance with the guidance from the Association of Chief Police Officers.
This relates to the specialist skills required by police officers in this sensitive area.

2.6. There is no automatic requirement for a 'forensic' home visit by a paediatrician following the death.

This does not preclude a home visit if the consultant paediatrician considers it appropriate and is able to do it. The principle to which we are working is that of high quality information collection on first contact in the A&E department. Northern Region paediatricians do not regard a routine home visit as either practical or feasible within current resources.

3. Death scene investigation

3.1. This should be a police responsibility.
There is general agreement among paediatricians that this requires a level of training and expertise that only the police possess, and that it would be both inappropriate, inefficient and probably ineffective for paediatricians to try to acquire skills that they would only very seldom deploy, and in which they could never become expert.

3.2. Where appropriate, the death scene should be imaged, and a copy of the images should be passed immediately to the pathologist, then placed in the clinical record. A proforma/checklist will be used as a decision aid for the need for imaging to ensure consistency.
This recognises that a workable alternative to the presence of a paediatrician at the death scene is desirable. However it may not always be appropriate to take stills or video of a death scene. Since it may be the only view that the pathologist can get of the death scene, it will be important to have consistency about which death scenes are imaged, and which are not.

3.3. Any images should be made available for review at the formal multi-disciplinary review meeting.
This point recognises that the interpretation of the death scene is enhanced by the involvement of people with local knowledge of the area (eg GP, health visitor). If it is to be of maximum value, it should be fed into the formal case review.

4. Skeletal Survey

4.1. Prior to the autopsy, a skeletal survey will be performed and provisionally reported, between 9am - 5pm including at weekends, as a minimum standard.
This acknowledges the fact that it is very unlikely that a specialist paediatric radiology opinion will be available before the pathologist conducts the autopsy. However even a provisional report from a radiologist is helpful to the pathologist, and specialist opinion can be sought at a later date where necessary. It is possible to undertake skeletal surveys at any general hospital in the region and to supply an interim report to inform the postmortem. Where Trusts can obtain skeletal surveys and reports out of hours this is ideal.

4.2. Skeletal surveys are regarded as mandatory in any child dying suddenly and unexpectedly under the age of 5 years. The police may request a skeletal survey on any child less than 18 years if there are unexplained injuries or abuse is suspected.
This recognises that any age limit is to some extent arbitrary. In practice, sudden unexpected death is very rare over the age of a year.

4.3. The skeletal survey and interim report are the responsibility of the hospital where the child is initially taken.
This is to ensure that there can be no question that an injury occurred while a body was being transported from one hospital to another. There will be very few occasions when a skeletal survey cannot be done in the hospital to which the child was first brought.

5. Post-mortem examination and pathology

5.1. Where maltreatment is suspected a Home Office Forensic Pathologist and a Paediatric Pathologist will undertake the post mortem jointly. If a Paediatric Pathologist is not available the post mortem will be undertaken by a Home Office Forensic Pathologist who will take samples in accordance with those outlined in the Kennedy Report.

5.2. Where maltreatment is not suspected a Paediatric Pathologist will undertake the post mortem. If a Paediatric Pathologist is not available the post mortem will be undertaken by a Home Office Forensic Pathologist who will take samples in accordance with those outlined in the Kennedy Report.
These paragraphs acknowledge the fact that with only one paediatric pathologist in the region, it will not always be possible to involve him in every autopsy. However the Royal College of Pathologists has a standard protocol for infant autopsies that the forensic pathologists follow, and the paediatric pathologist will always be able to review the histology subsequent to the autopsy.

5.3. If maltreatment is not suspected the police will nevertheless attend the post mortem to brief the pathologist about the facts that have been established. A scenes of crime officer (SOCO) will also attend to take photographs as requested by the pathologist.

5.4. As many records as possible, or copies of them, should be collated in the infant's hospital case record before the autopsy for inspection by the pathologist. Examples of relevant records are given under 7.2.
This is a crucial part of the early phase of information gathering that enables the pathologist to undertake the autopsy with maximum chances of making significant findings.

5.5. The baby should be transported to the mortuary at the RVI Newcastle.
This is now virtually always the case. It ensures that the autopsy is done where there are appropriate facilities with which to conduct it to a consistently high standard.

5.6. The results of tests taken prior to autopsy should be made known to the pathologist.
Not all test results will be available, but those that are should be transmitted promptly to the pathologist for the same reasons as with the background history.

6. Collation of other information

Any other relevant records as listed above but not available by the time of the autopsy should be collated and examined prior to the multidisciplinary meeting.
Those other records that are desirable, but cannot be obtained in time for the autopsy, still need to be found and kept together so that they can inform the multidisciplinary formal case review.

7. Multi-disciplinary formal case review

7.1. This would take the form of a critical incident review meeting for professionals, and its status should be regarded as being a component of the clinical governance/risk management framework of the agencies involved. It should have an independent professional chair.
This should enable a reasonably consistent approach to be taken region wide.

7.2. As many records as possible, or copies of them, should be collated in the infant's hospital case record before the meeting. Local guidance will be required with respect to the confidentiality issues in relation to third party information such as maternal obstetric records. Depending on the circumstances of the death, the relevant records might be:

- Information from interviews and scene of death, covering points listed in Kennedy appendix I, Durham Constabulary SUDI Policy etc
- Ambulance/paramedic record
- A&E record
- Other hospital records of the child
- Hospital records of the mother (especially obstetric notes)
- GP records
- Health visitor records
- Personal child health record book
- Any relevant police records
- Any relevant social services records
- Copies of any written statements subsequently made by professionals in any agency or discipline
- A copy of the autopsy report (see 7.3 below).

The quality and effectiveness of the meeting will be dependent on the amount of information that can be made available.

7.3. If the pathologist who carried out the autopsy does not feel it would be useful to be present, the results of the autopsy should be conveyed verbally to the paediatrician. A copy of the autopsy report should also be sought from the Coroner, although there may be circumstances in which its release may be regarded as inappropriate.
Although it would be ideal always to have the pathologist present, the realities of the unpredictable nature of forensic work will make this impractical. Other regions have found it entirely satisfactory when a verbal report is given to the lead paediatrician.

7.4. The Coroner should be notified of the meeting.
This will enable the Coroner either to join the meeting, or send a Coroner's officer, if they wish.

7.5. A report from the meeting should be sent to the Coroner.
The Coroners value this as an important contribution to their inquest. It will not be a detailed minute, but should be structured to state the consensus conclusions of the meeting.

8. **Parents**

8.1. Parents should be followed up by the consultant paediatrician who first met them in A&E.
There is general agreement that this is more appropriate than bringing in a third party at this stage.

8.2. Consent for the indefinite retention of blocks and slides will be requested routinely.
This is the provenance of the Coroner's officer.

APPENDIX 6 MEMBERSHIP OF STEERING GROUPS

Perinatal Mortality Survey (PMS/CEMACH) (current)

Dr Ruth Bell	Clinical Senior Lecturer
Dr Allan Colver	Consultant Paediatrician
Dr Tricia Cresswell	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
Mr Willie Reid	Consultant Obstetrician/ **Chair**
Mrs Marjorie Renwick	Regional CEMACH Manager
Dr Chris Wright	Consultant Perinatal Pathologist
Dr Jonathan Wyllie	Consultant Neonatologist

Northern Congenital Abnormality Survey (NorCAS) (current)

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

Multiple Pregnancy Register (current)

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

Diabetic Pregnancy Survey (current)

Dr Tricia Cresswell	Director RMSO/Director of Public Health
Prof John Davison	Consultant Obstetrician/**Chair**
Mrs Lisa Doughty	Diabetic Specialist Nurse
Dr Gillian Hawthorne	Consultant Diabetologist
Dr Nick Lewis-Barnard	Consultant Diabetologist
Mrs Marjorie Renwick	Operational Manager RMSO
Mrs Val Williamson	Diabetic Midwife
Mr Rob Wood	Consultant Obstetrician
Dr Bill Lamb	Consultant Paediatrician
Mr Stuart Hutchison	Consultant Obstetrician
Mrs Mary Bilous	Diabetic Specialist Nurse
Dr Maggie Blott	Consultant Obstetrician

NECCPS (current)

Dr Kailash N Agrawal	Consultant Paediatrician
Dr Nigel Brewster	Consultant Paediatrician
Ms Mary Bythell	RMSO Data Manager
Dr Allan Colver	Consultant Paediatrician/**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 Matilde Mans	Consultant Paediatrician
Dr Rosemary Menzies	Consultant Paediatrician
Dr Surendra Pandey	Consultant Paediatrician
Dr Sheila H Precious	Consultant Paediatrician
Ms Brenda Spilsbury	Children's Physiotherapist
Dr Maria Willoughby	Consultant Paediatrician
Ms Virginia Wood	Children's Physiotherapist

Appendix 7 RMSO staff and contact details

RMSO Staff and contact details

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