This newsletter marks the 5th anniversary of the Perinatal Institute (PI). Since our inception in April 2000, there have been a lot of changes within the NHS—the re-organisation of health authorities, emergence of PCTs as principal commissioners of care, the active programme of the National Screening Committee, the budget cuts and merger of CESDI and CEMD, CNST and the emergence of the Healthcare Commission, and the publication of the NSF for Maternity and Children’s Services.

The Perinatal Institute has also undergone changes. From the initial eight staff, there are now 36 of us in full or part time employ or secondments. We have a widened remit, addressing key aspects of the whole spectrum of maternity and infant health.

This newsletter lists the main activities of the Perinatal Institute, with www -links to further information. Our objectives address the NHS goals of equity, safety, and choice, and are summarised in the document ‘Delivering Enhanced Perinatal Care’:
- Improving patient safety and reducing avoidable perinatal loss
- Enhancing maternity care and delivering the public health agenda
- Antenatal and neonatal screening and monitoring congenital anomalies
- Information and choice for mothers and good record keeping
- Standardised electronic collection of maternal and neonatal data

We would like to use this opportunity to thank all those who continue to assist us with this work—midwives, obstetricians, neonatologists and neonatal nurses, public health specialists, local coordinators and many associated health specialists, as well as the users/patient advocates on our various advisory groups. I would also like to thank my staff for their dedication and hard work, without which none of our past achievements and future aspirations would be possible.

Professor Jason Gardosi - Director

Our key focus is to work towards understanding and prevention of adverse perinatal outcome. This work is carried on in several streams.

**Perinatal Mortality.** Rates of stillbirths and neonatal deaths are regularly updated on the website by Andre Francis, our statistician, and include regional and SHA area statistics. Due to small numbers, deaths by PCT are potentially identifiable and are therefore not published but sent only to each PCT and maternity unit.

**West Midlands stillbirths 1998 -2003.** We have recently concluded an analysis using our new classification system for stillbirth (ReCoDe - Relevant Condition at Death) which reduced the proportion of 'unexplained' deaths from 66% to 16%. The analysis confirmed fetal growth restriction as the single largest factor.

**Social deprivation and perinatal and infant mortality** was also assessed and suggests that the inequalities gap is not diminishing but in fact getting larger. We are dealing with an increasing number of data requests by PCTs, SHAs and Trusts for local equity audits. Applications require the appropriate data confidentiality forms.

**Diabetes in Pregnancy.** The PI assists the current CEMACH Confidential Enquiry by contributing anonymised cases to the national pool. Our panel assessments are however undertaken for cases which occurred in the West Midlands, as requested by our stakeholders. This will allow us to look at questions of special relevance in the WM, such as those concerning ethnic minorities and the large number of Type 2 diabetes. The regional enquiry is led by Dr Fidelma Dunne and Mr Bill McKenzie, and regular panels have been held in various parts of the region. The study will report in early 2006.

**The Stillbirth and Neonatal Death Society (SANDS)** are extending their excellent support work for bereaved parents, and are working with the PI to roll out our RAPID workshops (Reducing Avoidable Prenatal and Infant Deaths) across their national network. We recently hosted a national meeting of SANDS co-ordinators and are planning a joint conference on Stillbirths: Causes and Strategies for Prevention, on 8 June 2005.

**Maternal Deaths.** Following further cuts in their budget, CEMACH has moved the administration of the WM maternal death enquiries to be carried out centrally from April 2005. After the publication of the last ‘Why Mothers Die’, the PI invited the authors to present their findings at two Perinatal Forums earlier this year. There was wide interest, and a main action point was that we explore the feasibility of conducting maternal near-miss enquiries in the West Midlands. A special Forum on this has been arranged for 21 June 2005.
Following on from our report on the Bellevue Project on Primary Care and Integrated Maternity Services (PC-AIMS), a Maternity Services Group chaired by Bridget Nisbet looked at the underlying principles of mother and baby-oriented, midwife-led, community-based maternity care.

This work dovetailed with the Reducing Perinatal Mortality project of the Birmingham and the Black Country’s ‘PCT Accord’. This is co-ordinated by Suzanne Jones, consultant in public health, who is seconded to the PI part time. Suzanne convenes a project team representing all twelve PCTs. The long term aim is the reduction of avoidable perinatal deaths, with three agreed proxy indicators being 1. early first visit, 2. continuity of care by primary caregiver, and 3. antenatal detection of fetal growth restriction.

The PI is hosting the new Maternal and Infant Strategic Health Network (MISHN) which was convened on the initiative of the national SHA chairs, with Elisabeth Buggins, Chair of BBCHA. The aim is to define common priorities and develop strategies for enhancing care for mothers and infants, in line with the NSF and performance assessment and enhancement. MISHN has representation from each SHA in England, the Healthcare Commission and various user groups.

Minutes of meetings are archived on the web.

**Antenatal and Child Health Screening**

The PI supports the regional antenatal and newborn/child health screening programmes to modernise and standardise service provision in line with directives from DH and the National Screening Committee (NSC). We are also collaborating with the Regional Director of Public Health and the Strategic Health Authorities to review quality assurance mechanisms for screening programmes across the West Midlands. A current risk assessment review is underway by the regional co-ordinators.

**Antenatal Screening**

There is now an infrastructure in place with a Local Co-ordinator / Specialist Midwife in all 20 maternity units in the region, some with deputies and/or clerks for support. This network meets monthly, facilitated by Sharon Hodgkiss as Regional Co-ordinator. Debra Foster has been appointed as Education & Training Facilitator to provide support with training initiatives and development of pre and post registration multidisciplinary modules.

**Down’s Syndrome & Fetal Anomalies.** National standards are in place since April 2004 with a clear timescale for development up to 2007. There is strong support to move to first trimester screening, and the PI has developed proposals for a novel method of contingency screening which takes account of the current capacity for ultrasound services in the region. The NSC is currently assessing this proposal.

**Sickle Cell & Thalassaemia.** In conjunction with the neonatal sickle cell screening programme, universal antenatal screening has been implemented in areas of high prevalence. A comprehensive report of services and developments over the last 2 years is available. Policy decisions regarding low prevalence areas have been developed with a pilot of ‘the family origin question’ and PEGASUS genetics training commencing in Shrewsbury this summer. Fast-track training has been delivered across the region to all core professionals to raise knowledge and awareness of the conditions and the implementation of the linked screening programmes.

**Infectious Diseases.** The NSC is currently liaising with the Regional Co-ordinators, Regional Epidemiologists and Health Protection Agencies to co-ordinate auditing and monitoring of services and adherence to DoH targets and directives. An initial report on surveillance strategies will be available in summer 2005.

**Audit & Monitoring.** A module of the MANNERS web-based data collection system allows audit of all screening programmes in line with DoH and NSC standards and directives. It is already in use in 18 WM maternity units. The PI is developing a template to enable local co-ordinators to produce a comprehensive report to Trusts, PCTs & SHAs in 2006.

**Ultrasound.** The PI convenes the Regional Ultrasound Group (RUG). We jointly carry out ultrasound audits and discuss and agree on regional standards. The work includes:

- Guidelines for dating by ultrasound rather than LMP now a standard in all WM units.
- ARC training programmes on communication skills for sonographers.
- Workshops on ultrasound and Doppler.
- Short courses for midwives on first and third trimester scans, in collaboration with the University of Central England.
- A Soft Marker policy which standardises information given to patients.
- Regional ultrasound survey. This was published in Sept 2004 and indicated a relatively consistent approach to ultrasound in the region. The main area of concern was the shortage of staff.
Child Health Screening

The success of the co-ordinated approach to antenatal screening programmes led in 2004 to the NSC proposal for nine regional Child Health Screening Co-ordinators. Glenda Augustine was appointed as regional Child Health Screening Co-ordinator, also fulfilling the role of lead national co-ordinator. The objective is to implement new, and modernise existing, child health screening programmes, initially concentrating on the newborn period.

In parallel with the Antenatal programme, a newborn and child health screening advisory group has been established, with the primary function to advise on the regional implementation of the national screening programme. The development of multidisciplinary networks will ensure the spread of good screening practice and address inequity.

Newborn Bloodspot Screening: National standards were introduced by the UK Newborn Bloodspot Programme in December 2004 and have been implemented by the West Midlands Regional Newborn Screening Laboratory in April 2005. The NSC has proposed the phased introduction of newborn screening for cystic fibrosis by 2007. This will require the delivery of training and co-ordination of counselling and support services prior to implementation.

Newborn Hearing Screening Programme: This structured programme is co-ordinated on a local and national level with detailed protocols and patient journey flowcharts. It is in the final phase of implementation across the West Midlands, with five outstanding sites to commence screening by October 2005.

Physical Examination of The Newborn: The NSC recommends an initial examination of the newborn within the first 72 hours of birth and a further examination at 6 – 8 weeks. There are a number of issues that impact upon the delivery of this programme and the PI is currently reviewing the variance across the West Midlands.

Congenital Anomaly Register (WMCAR)

- WMCAR is now receiving electronic notifications via a module of MANNERS.
- The three-region research study on Gastroscisis will report later this year. The results will be presented at the Perinatal Forum on 13 September 2005.
- An update on Congenital Diaphragmatic Hernia includes detection rate by ultrasound and a profile of survival for isolated and complex cases.
- A recent update of our Down’s report includes, for the first time, data on effectiveness of screening in affected cases.
- A study is nearing completion to map congenital anomalies to landfill sites. The project is run in conjunction with the Health Protection Agency and Birmingham University.
- Parent Information: An Anomaly Resource Pack has been produced for each WM Antenatal Screening Co-ordinator. The pack is supported by its website and contains literature produced by charities and hospitals on the main congenital anomaly groups.

Information for Mothers, Choice and Record Keeping

Pregnancy Notes

The antenatal notes have been developed in line with recommendations from CESDI reports and the NSF, and are a means to ensure that expectant mothers have information about their care and options. They aim to highlight risk factors and facilitate good record keeping. The notes are now in standard use in the West Midlands and an increasing number of units elsewhere throughout England, Wales and Northern Ireland. They are supplied only after comprehensive training. The next national workshop is on 6 July 2005.

The notes are being continually updated in response to user feedback and amended NHS policies. A survey in 2004 has confirmed wide support but also provided useful suggestions which have been implemented. The Notes link in with the MANNERS dataset, and inform mothers about data collection for secondary analysis and how to opt out.

An Urdu translation is due for release soon.

Birth Notes

The new intrapartum record incorporates recommendations from the national Confidential Enquiries on risk assessment, good record keeping and reduction of substandard care. Following wide consultation and field trials, the notes were launched recently and are already in routine use in 14 maternity units.

Postnatal Notes

We have held several consultative meetings with key stakeholders, and are about to produce the first version for field trials. Launch is expected later this year.
Customised Fetal Growth Charts

A key component of the Pregnancy Notes are the customised antenatal charts, and our liaison midwives have rolled out an active training programme for the assessment of fetal growth, including standardised fundal height measurement, use of the software and care pathways for referral. Following initial concerns of a possible increase in scan referrals, an audit was undertaken through the Regional Ultrasound Group which showed that:

- the total of new referrals for growth scans was only 6% of the obstetric ultrasound workload
- referrals were appropriate in 82% of cases
- most inappropriate referrals were for suspected large for gestational age babies

The audit led to the refinement of guidelines for ‘LGA’ referrals. A larger audit is in progress to assess use and effectiveness of fetal growth assessment.

Standardised Electronic Collection of Data

Much of our understanding of good practice and adverse outcomes depends on quality data, the collection of which is a key focus of the Perinatal Institute. The Maternal And Neonatal Electronic Recording System (MANNERS) is being developed for three applications, each of which are underpinned by core datasets determined following wide consultation. Our data security and confidentiality policies are summarised on the MANNERS web pages.

Neonatal. Data collection has been up and running since 2003, from all neonatal units in the West Midlands. The first annual report was released in January 2005 and provides a wealth of data, welcomed by clinicians and commissioners alike. Further work is currently underway to assist units with reviewing and validating their own data and to improve software functionality.

The Paediatric High Dependency Data Project is off and running, and a professional advisory group has been established. The project collects data from all commissioned units in the WM and the first report has been completed. Current work focuses on increasing the dataset to add clinically relevant fields to assist with auditing against the ‘Standards for the Care of Critically Ill & Critically Injured Children in the West Midlands’.

Maternity. The MANNERS maternity module seeks to capture information about all mothers and babies, i.e. denominator data. This will be of great benefit in understanding the causes and variations in perinatal morbidity and mortality, and to monitor the progress of service developments and public health initiatives. The system is NN48-enabled and uses the NHS number as the unique identifier.

There are many useful functionalities summarised in a recent document. Field trials have been completed and the module is being implemented in the first units in the West Midlands. At the same time, work is underway with the LSP in our cluster to make the system NPfIT compliant and compatible with new PAS systems.

The PI is in contact with various strands of the National Programme for IT (‘NHS - Connecting for Health’) to ensure that maternity is high up on their list of priorities.

We are hosting a national meeting on NPfIT for Maternity Services in May.

Research. We are currently engaged in studies to map social deprivation and adverse perinatal outcome, fetal growth and maturation in diabetes, and the pathology of stillbirth. Internationally, collaborative projects include fetal growth and ethnicity (Auckland, Sydney), multiple pregnancy (Miami), and cerebral palsy (Goteborg) (gestation.net/projects). We are also working with WHO to develop applicable systems and tools for perinatal audit.

Facilities. Since our move to larger offices, we have been able to host a number of other regional and national groups to which our work relates, including the WM Maternity Services Liaison Group, Regional Network of Advisors for Smoking Cessation in Pregnancy, Regional Midwifery Forum, WM Child Health Record Group, Obstetric HRG v4 -EWG, and the Mothers and Infants Strategic Health Network (MISHN).

Our lecture theatre and board room are also available for hire (perinatal.nhs.uk/facilities)

Perinatal Forums - forthcoming meetings in 2005 (details / updates on perinatal.nhs.uk/diary)

- May 18 NPfIT for Maternity Services
- June 8 Stillbirths & Strategies for Prevention
- June 21 Maternal Near Miss Enquiries
- Sept 13 Gastrochisis
- Oct 18 Multiple Pregnancy
- Nov 17 Antenatal & Neonatal Screening
- Dec 6 Confidential Enquiries into Children’s Deaths

Miscellaneous

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