NATIONAL PERINATAL EPIDEMIOLOGY CENTRE

ANNUAL REPORT 2009
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Introduction

A note from Prof. Richard Greene:

In the first couple of years since the inception of the National Perinatal Mortality Centre, we have endeavoured to lay the groundwork for providing Irish maternity services with a facility to undertake in-depth reviews of its own medical practices, through monitoring outcomes and regular audit. Measurement of the outcome of care is central to the development of safe and high quality services, and I, as a consultant Obstetrician and Gynaecologist and Director of NPEC, am committed to improving patient care in Ireland’s maternity services.

Much of the initial work of NPEC has focused on generating a national knowledge among the maternity services and building a consensus for the Centre. The feedback from maternity units and hospitals around the country has been encouraging: many personnel are now aware of NPEC and its mission, and we have experienced an overall feeling of good will towards the Centre and what we wish to achieve. Reporting data to NPEC is not a statutory requirement, but in 2009, all 20 maternity units voluntarily provided some obstetric and neonatal data to the Centre, demonstrating the consensus that exists to have such data examined at a National level.

Whilst all maternity units have become busier in recent years due to the increased birth rate and the recruitment moratorium within the Health Service Executive, it is laudable that personnel make the effort to supply the data required for audit and review of the service provided to the mothers and babies at their unit. Given that many units hold paper records, as opposed to electronic records, it is often time-consuming and difficult to retrieve these records. To this end, NPEC is highly appreciative of the efforts made by the many midwives, administration staff, obstetricians and neonatologists.

Currently, at NPEC, we are working on projects concerning maternal morbidity; neonatal morbidity and survival; as well as formulating and implementing systems for the reporting of all perinatal mortalities and maternal morbidities occurring in Ireland’s 20 maternity units. The Centre for Maternal and Child Enquiries (CMACE Ireland), which investigates cases of maternal mortality, is supported by NPEC. Additionally, the Centre holds the license for access to the Vermont Oxford Network in Ireland, a collaboration of healthcare professionals dedicated to improving the medical care of newborn infants.

In 2009, we initiated a number of specialist sub-groups under the auspices of NPEC. One of these such groups was the Perinatal Mortality Group, the aim of which is to develop a nationwide surveillance programme on perinatal mortality in Ireland. The Group is made up of a number of midwife managers, paediatricians, obstetricians and a pathologist. NPEC’s research midwife, Edel Manning, has worked closely with the Group to collect and analyse perinatal mortality data from 2008 going forwards. Data for the year 2008 is presented on pages 7-15 of this report. NPEC and the Perinatal Mortality Group, have also undertaken an analysis of individual maternity unit data for all but the larger units in the country, and distributed unit-specific reports to 16 units for the
year 2008. This constitutes a means by which units can appraise their own perinatal mortality record, and compare it (anonymously) with other units around the country, which they previously did not have the facility to do.

Another sub-group established by NPEC in 2009 was the NPEC National Advisory Group. As its name suggests, this is an advisory group designed to support the Centre in the achievement of its mission, and particularly to address issues relating to access by clinicians and researchers to NPEC data for research purposes. Membership of the group represents a diverse range of key stakeholders from many maternity units and universities in the country.

In 2009, we welcomed a number of new staff to the Centre, including an epidemiologist, a research midwife, a data analyst and an administrator. We hope to continue to expand in 2010 and are making plans to engage 2 PhD students and 2 summer interns to work on specific research projects.

All at NPEC remain encouraged by the support for its mission that is evident amongst maternity services personnel. I would like to thank all those who have been supportive to date. Together we have great potential to improve the care of mothers and babies in Ireland. I would also like to thank the staff of NPEC for their support and endeavour to the mission. We look forward to a challenging and fruitful 2010.

*Richard A Greene*
*Director*
In 2009, NPEC welcomed 4 new staff members. Prof. Mona Lydon-Rochelle, Ms Edel Manning, Dr. Linda Drummond and Ms. Eileen Barry started their work for NPEC in the summer months, following the departures of Ms Kathryn Neville and Ms Anne Burke. Each was recruited to NPEC after a competitive selection process. Additionally, NPEC hired a Data Analyst, Ms Jennifer Lutomski, at the end of 2009: Jennifer will begin her work with NPEC in January 2010.

**Prof. Mona Lydon-Rochelle - Perinatal Epidemiologist**
Mona comes to NPEC from Seattle, Washington, USA. She obtained a BS with distinction from the University of New Mexico (1989) and an MS with honours from Case Western Reserve University (1991). She undertook her MPH (1994-1996) and PhD (1997-1999) at the University of Washington, Seattle, where she studied the impact of method of delivery on the short, medium, and long-term health of women.

Mona’s primary research interests are in the areas of perinatal epidemiology. Recent perinatal epidemiology research projects include the assessment of the accuracy of birth certificates and hospital discharge data; patterns of indications for labour induction; examining medical indications for caesarean delivery; and risk factors for trial of labour following caesarean delivery.

**Edel Manning – Midwife Co-ordinator**
Edel Manning comes to NPEC from the Coombe Women and Infants University Hospital. She is a registered nurse and midwife, as well as a qualified sonographer in Obstetrics and Gynaecology.

Edel undertook her midwifery training in the Coombe and subsequently gained her clinical experience in the labour ward there, first as a midwife and then as a Clinical Midwife Manager 2. Having completed training in diagnostic ultrasound of Obstetrics & Gynaecology, she transferred to the Ultrasound Department in 2004 where she practiced as a clinical midwife specialist prior to joining NPEC in May 2009.

**Dr. Linda Drummond – Research Administrator**
Linda Drummond is a research co-ordinator and administrator with NPEC. Prior to joining the centre in June 2009, Linda held the position of research co-ordinator at the Alimentary Pharmabiotic Centre, UCC where she was instrumental in setting up the Germ-Free Unit there. Linda’s background is in biology: she received her Ph.D. from UCC in 2006 on the subject of health and disease of Manila clams in Ireland. Linda has previously held research positions at the Department of Zoology, UCC; and has spent periods working on research projects at the University
of Santiago de Compostela, Spain; the Australian Institute of Marine Science; and the Institute of Marine Biology of Crete.

**Ms Jennifer Lutomski – Data Analyst**

Jennifer received an MSc in epidemiology from the New York State School of Public Health at Albany, USA and also possesses a Certificate of Graduate Study in social demography. Prior to joining NPEC, Jennifer worked for the Department of Epidemiology and Public Health, UCC, and was a researcher on the consortium for the Survey of Lifestyle, Attitudes and Nutrition (SLÄN), as well as the Safefood study of dietary salt intake in the Irish population. She also facilitated the Cork and Kerry Heart Disease and Diabetes 10-year follow-up study and has also previously worked for the National Suicide Research Foundation.

Jennifer maintains a strong interest in data management and quantitative analysis. Her particular research interests include child and maternal health, obesity and minority health disparities.

**Eileen Barry - Administrator**

Eileen Barry joined the staff of NPEC in July 2009. Eileen holds joint positions with NPEC and the Department of Obstetrics & Gynaecology, UCC. Prior to joining the Department, Eileen worked in the Finance Office, UCC for over twenty years.
The Perinatal Mortality Group was established in early 2009 for the purpose of developing a surveillance programme on perinatal mortality in Ireland. The fundamental aim of this programme is to contribute to improvement in Irish perinatal outcomes, through the provision of key epidemiological evidence.

The Group has set out to fulfil its purpose by developing a nationwide surveillance programme and by carrying out a confidential enquiry into cases of perinatal mortality. The Group will also collect and report information on all babies greater than 500g delivering without life, and any live born baby dying within 28 days after delivery, as part of its mortality surveillance work. The Group will provide timely data on perinatal deaths in the form of an annual national perinatal mortality report for hospitals with maternity services, within 12 months of the year end. Additionally, it will monitor and report on all perinatal deaths and their causes in Ireland, in a format that is meaningful to the relevant health bodies e.g. HSE, DOHC, professional organizations (RCPI, IOG, Faculty of Pathology, Academy of Paediatrics) and other organizations (Irish Perinatal Society).

The Group will make use of data collected by NPEC using the NPEC dataset. This dataset contains the anonymised clinical and demographic details of every birth in the country. The dataset was completed in 2008, following a review of similar sets in use internationally, and contains input from Obstetric Consultants, Directors of Midwifery, as well as Nursing and Administrative staff.

Overall, the Perinatal Mortality Group aims to contribute to activities working to improve perinatal mortality through the provision of key epidemiological evidence by:

- Providing ongoing quality, timely epidemiological data on perinatal deaths, for the purposes of informing health policy, service planning and further research, and benchmarking at a local, regional and national level;
- Developing a national model for perinatal mortality review and surveillance and allow for international comparison;
- Providing healthcare organizations with high quality, timely mortality data;
- Examining clinical care prior to perinatal death and using this information to make recommendations for the improvement of clinical care, where appropriate;
- Providing findings relating to perinatal mortality that can assist national guidelines and clinical advice via partnerships with the Institutes, Colleges, HSE and other guideline or audit development groups;
- Providing data to researchers, planners, healthcare organizations and policy makers in public health on the major “clinical” and “non-clinical” risks associated with perinatal death;
• Identifying and promulgating areas for further research on perinatal mortality and morbidity.

**Members of the Perinatal Morality Group**
- Ms Bridget Boyd, Coombe Women and Infant’s Hospital
- Dr Patricia Crowley, Coombe Women and Infant’s Hospital
- Dr Elizabeth Dunn, Wexford General Hospital
- Ms Oonagh McDermott, Sligo General Hospital
- Dr Eoghan Mooney, National Maternity Hospital
- Ms May Quirke, Tralee General Hospital
- Ms Ann Rath, National Maternity Hospital
- Dr John Slevin, Midwestern Region Maternity Hospital Limerick
- Dr Anne Twomey, National Maternity Hospital
- Ms Patricia Williamson, Rotunda Hospital
- Dr. Siobhan Gormally, Our Lady of Lourdes Hospital

**Future Plans for the Perinatal Mortality Group**
The Perinatal Mortality Group meets on a bi-annual basis. As the Group becomes more cohesive and its fledgling issues are overcome, it will move closer to meeting its mission. To this end, a report on the 2008 NPEC perinatal data is included in this current report, and a perinatal mortality report for each individual maternity unit has been generated and sent to each unit (for 16 of the 20 units in the country). The NPEC data collection process continues.

*See Appendix A for minutes of PMG meetings held in 2009.*
PERINATAL DATA COLLECTION
AND
THE NATIONAL PERINATAL MORTALITY REPORT 2008

1. Introduction

Edel Manning, NPEC’s research midwife co-ordinator, has the responsibility for collecting Irish maternity unit data on behalf of the Perinatal Mortality Group and NPEC. To date, Edel has visited and liaised with all of the 20 maternity units in Ireland. Specifically, she has endeavoured to identify the data recording procedures for perinatal mortality events in each maternity unit; ascertain the clinical audit practices in each unit; and undertake an audit of perinatal mortality rates on all births in Ireland.

2. Methods

To begin the surveillance process, NPEC provided a dataset to all maternity units in the country. In most units, the dataset was completed by a senior midwife. Data items included maternal age; parity; mode of delivery; birth weight; gestation at delivery; autopsy status and cause of death. The terms of reference for inclusion of perinatal mortality events in the dataset was set at: stillborn babies ≥ 500g; and neonatal deaths ≥ 500g dying within the first seven days of life.

The first set of data collected was for the year 2008. A total of 17 units provided NPEC with their anonymised perinatal mortality data for this year, and a further 3 units provided data from their published 2008 annual clinical reports. The data was subsequently entered into the NPEC database. The cause of death in stillbirths and neonatal deaths was classified using the extended Wigglesworth Classification System (Table 1). The data was analysed and reviewed by the Perinatal Mortality Group.

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Table 1: Wigglesworth Classification System for Cause of Perinatal Death

- Category 1: Congenital defect/malformation (lethal/severe)
- Category 2: Unexplained antepartum fetal death
- Category 3: Death from intrapartum ‘asphyxia’, ‘anoxia’ or ‘trauma’
- Category 4: Immaturity, applies to live births only
- Category 5: Infection
- Category 6: Other specific causes – specific recognisable fetal, neonatal or paediatric condition not covered under earlier categories
- Category 7: Accident or non-intrapartum trauma
- Category 8: Sudden infant death, cause unknown
- Category 9: Unclassifiable
3. Results

The first issue this initial contact and data collection process highlighted is the wide variance in data recording practices amongst maternity units. Ten units use an electronic database, although these are not uniform, and represent various datasets, many of which do not have a neonatal component. Eight units do not have an electronic database, but record clinical data on perinatal death in patient charts. Two units collect delivery data electronically, but record perinatal events in patient charts (Figure 1).

Secondly, the recording of perinatal mortality events in Irish maternity units is often influenced by a number of key factors. For example, the provision of an individual personnel member specifically dedicated to clinical audit and data collection, within a unit, is highly significant: this is true of units, both, with and without an electronic database. Additionally, whether a unit holds regular perinatal mortality meetings, in which perinatal mortality cases are reviewed, or publishes an annual clinical report, has been shown to have a bearing on the data collection process. Historically, only the three Dublin maternity hospitals have consistently published an annual report, but in recent years, the number of units reporting has increased.
Figure 1: Maternity Units in Ireland

Availability of an Electronic Database
3.1. Perinatal Mortality Rate

In 2008, there were 75,421 births having a birth weight equal to or above 500g in Irish maternity units. The Perinatal Mortality Rate (PMR) was 6.8 per 1000 births, and the corrected PMR (for lethal/potentially lethal malformation) was 4.9 per 1000 births (Table 2). Of the PMR, the stillbirth (SB) rate was 4.7 per 1000 births and the neonatal death (NND) rate, 2.1 per 1000 births (Table 2). The PMR ranged between 3.1 and 8.6 per 1000 births for individual units (Table 3).

Table 2: Perinatal Mortality Summary Statistics for All Irish Maternity Units Combined in the Year 2008

<table>
<thead>
<tr>
<th>Summary</th>
<th>Rate/Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Number of Births ≥ 500g</td>
<td>75,421</td>
</tr>
<tr>
<td>Total Number of Perinatal Deaths</td>
<td>512</td>
</tr>
<tr>
<td>Stillbirth Rate</td>
<td>4.7 per 1000</td>
</tr>
<tr>
<td>Neonatal Death Rate</td>
<td>2.1 per 1000</td>
</tr>
<tr>
<td>Perinatal Mortality Rate (PMR)</td>
<td>6.8 per 1000</td>
</tr>
<tr>
<td>Corrected PMR for Congenital Malformation</td>
<td>4.9 per 1000</td>
</tr>
</tbody>
</table>

PMR is calculated as follows:

\[
\text{PMR} = \frac{\text{No. of Stillbirths} \geq 500g + \text{No. of Early Neonatal Deaths} \geq 500g \times 1000}{\text{No. of Live Births and Stillbirths} \geq 500g}
\]

Table 3: Perinatal Mortality Rate (PMR) and corrected PMR for congenital malformation in individual Irish maternity units for the year 2008

<table>
<thead>
<tr>
<th>Hospital</th>
<th>PMR per 1000 births</th>
<th>95% Confidence Interval</th>
<th>Corrected PMR per 1000 births</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.6</td>
<td>1.7 - 7.4</td>
<td>3.2</td>
<td>0.8 - 5.6</td>
</tr>
<tr>
<td>2</td>
<td>6.8</td>
<td>5.1 - 8.5</td>
<td>5.0</td>
<td>3.5 - 6.5</td>
</tr>
<tr>
<td>3</td>
<td>8.7</td>
<td>4.9 - 12.3</td>
<td>5.8</td>
<td>2.7 - 8.8</td>
</tr>
<tr>
<td>4</td>
<td>7.3</td>
<td>3.6 - 11.0</td>
<td>3.4</td>
<td>0.8 - 5.9</td>
</tr>
<tr>
<td>5</td>
<td>4.0</td>
<td>1.4 - 6.6</td>
<td>3.1</td>
<td>0.8 - 5.4</td>
</tr>
<tr>
<td>6</td>
<td>7.8</td>
<td>4.1 - 11.5</td>
<td>6.4</td>
<td>3.1 - 9.8</td>
</tr>
<tr>
<td>7</td>
<td>6.4</td>
<td>2.8 - 10.0</td>
<td>4.8</td>
<td>1.6 - 8.0</td>
</tr>
<tr>
<td>8</td>
<td>4.1</td>
<td>1.3 - 6.9</td>
<td>4.1</td>
<td>1.3 - 6.9</td>
</tr>
<tr>
<td>9</td>
<td>3.1</td>
<td>0.6 - 5.7</td>
<td>2.0</td>
<td>0.1 - 4.2</td>
</tr>
<tr>
<td>10</td>
<td>5.8</td>
<td>2.8 - 8.7</td>
<td>5.0</td>
<td>2.3 - 7.7</td>
</tr>
<tr>
<td>11</td>
<td>5.3</td>
<td>1.8 - 8.8</td>
<td>4.1</td>
<td>1.0 - 7.2</td>
</tr>
<tr>
<td>12</td>
<td>2.6</td>
<td>0.1 - 5.1</td>
<td>1.9</td>
<td>0.2 - 4.1</td>
</tr>
<tr>
<td>13</td>
<td>7.6</td>
<td>2.6 - 12.6</td>
<td>3.3</td>
<td>0.1 - 6.7</td>
</tr>
<tr>
<td>14</td>
<td>8.1</td>
<td>6.2 - 9.9</td>
<td>5.7</td>
<td>4.1 - 7.2</td>
</tr>
<tr>
<td>15</td>
<td>6.5</td>
<td>4.8 - 8.1</td>
<td>4.2</td>
<td>2.8 - 5.5</td>
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<tr>
<td>16</td>
<td>7.8</td>
<td>5.9 - 9.6</td>
<td>4.6</td>
<td>3.1 - 6.0</td>
</tr>
<tr>
<td>17</td>
<td>8.6</td>
<td>5.2 - 12.0</td>
<td>8.3</td>
<td>5.0 - 11.6</td>
</tr>
<tr>
<td>18</td>
<td>6.9</td>
<td>4.7 - 9.1</td>
<td>5.3</td>
<td>3.7 - 7.2</td>
</tr>
<tr>
<td>19</td>
<td>7.8</td>
<td>5.2 - 10.5</td>
<td>7.1</td>
<td>4.6 - 9.7</td>
</tr>
<tr>
<td>20</td>
<td>6.5</td>
<td>3.9 - 9.1</td>
<td>4.6</td>
<td>2.4 - 6.8</td>
</tr>
</tbody>
</table>

Note: All maternity units have been randomly assigned with numbers 1-20, with no significance in order.
3.2. Maternal Characteristics of Perinatal Loss

3.2.1. Maternal Age

The age distribution of mothers experiencing perinatal loss was similar in proportion to the overall Irish child-bearing population in 2008 (CSO, 2009) (Table 4). Four percent of perinatal losses occurred in women under the age of 20 and 5% in women over the age of 40 (Table 4).

Table 4: Age profile of mothers experiencing perinatal loss

<table>
<thead>
<tr>
<th>Maternal Age</th>
<th>Perinatal Deaths (%) (95% CI*) n=512</th>
<th>All Births CSO* (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;20</td>
<td>4 (3 – 6)</td>
<td>3</td>
</tr>
<tr>
<td>20-24</td>
<td>17 (13 – 20)</td>
<td>12</td>
</tr>
<tr>
<td>25-29</td>
<td>22 (18 – 26)</td>
<td>24</td>
</tr>
<tr>
<td>30-34</td>
<td>30 (25 – 34)</td>
<td>34</td>
</tr>
<tr>
<td>35-40</td>
<td>22 (18 – 26)</td>
<td>23</td>
</tr>
<tr>
<td>&gt;40</td>
<td>5 (3 – 7)</td>
<td>4</td>
</tr>
</tbody>
</table>

*CI: Confidence Interval; CSO: Central Statistics Office

3.2.2. Parity of Women Experiencing Perinatal Loss

The results showed that slightly more stillbirths occurred in multiparous mothers (55%) than in primiparous mothers (45%), from a total of 358 stillbirths in 2008. Similarly, 58% of neonatal deaths occurred in multiparous mothers and 42% in primiparous mothers: the total number of neonatal deaths being 154 in 2008.

3.3. Mode of Delivery

Spontaneous vertex delivery was the most common mode of delivery for both stillbirths (76%) and neonatal deaths (43%) (Table 5). Caesarean section was the mode of delivery for 40% of babies who were subsequent neonatal deaths.

Table 5: Mode of delivery in women undergoing perinatal loss

<table>
<thead>
<tr>
<th>Mode of Delivery</th>
<th>Stillbirth (%) n=358</th>
<th>Neonatal Death (%) n=154</th>
</tr>
</thead>
<tbody>
<tr>
<td>SVD</td>
<td>76</td>
<td>43</td>
</tr>
<tr>
<td>LSCS</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>Vaginal Breech</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Ventouse</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Forceps</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Not stated</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

SVD = Spontaneous Vertex Delivery; LSCS = Lower Segment Caesarean Section
3.4. **Causes of Perinatal Death**

Using the Wigglesworth Classification System (Table 1), the leading cause of death in stillbirths was categorised as unexplained in 46% of cases, followed by congenital anomaly in 19% of cases (Figure 2a). With regard to neonatal deaths, congenital malformation (lethal/severe) was the leading cause, accounting for 49% of deaths, followed by immaturity, accounting for 27% of deaths (Figure 2b). Figures 2a and 2b depict the leading causes of death in stillbirth and neonatal death, respectively, on a national level for the year 2008.

**Wigglesworth Classification - Stillbirths (n=358)**

![Stillbirths Chart]

Figure 2a: National percentage distribution of cause of death in stillbirths for the year 2008. Figures represent data provided by all 20 Irish maternity units.

**Wigglesworth Classification - Neonatal Deaths (n=154)**

![Neonatal Deaths Chart]

Figure 2b: National percentage distribution of cause of death in neonatal deaths for the year 2008. Figures represent data provided by all 20 Irish maternity units.
3.5. **Autopsy uptake**

The overall autopsy rate was 44.5%. Autopsy uptake was less likely in the case of neonatal deaths (34%) compared to stillbirths (49%).

3.6. **Birthweight and Gestational Age of Stillbirths**

Some 40% of stillbirths had a birth weight less than 1500g and 67% had a birth weight of less than 2500g (Figure 3a). With respect to gestational age, 21.5% of stillbirths were less than 28 weeks at delivery (Figure 3b).

![Birthweight distribution](image1)

**Figure 3a**: National percentage distribution of birth weight in stillbirths for the year 2008. Figures represent data provided by all 20 Irish maternity units.

![Gestation distribution](image2)

**Figure 3b**: National percentage distribution of gestational age at delivery in stillbirths for the year 2008. Figures represent data provided by all 20 Irish maternity units.
3.7. **Birthweight and Gestational Age in Neonatal Deaths**

Half of all neonatal deaths in 2008 had a birthweight of less than 1500g and 72% weighed less than 2500g (Figure 4a). The largest category (28%) of neonatal death birthweight occurred at 500-749g. With respect to the gestational age of neonatal deaths, there were two peaks: one at less than 28 weeks, accounting for 37% of neonatal deaths, and another at 37-41 weeks gestation, accounting for 34% of neonatal deaths (Figure 4b).

![Birthweight - Neonatal Deaths (n=154)](image)

Figure 4a: National percentage distribution of birth weight in neonatal deaths for the year 2008. Figures represent data provided by all 20 Irish maternity units.

![Gestation at Delivery - Neonatal Deaths (n=154)](image)

Figure 4b: National percentage distribution of gestational age at delivery in neonatal deaths for the year 2008. Figures represent data provided by all 20 Irish maternity units.
4. Discussion

This is the first nationwide assessment of perinatal mortality from a clinical viewpoint, in Ireland. The scope of data collected was deliberately limited in order to make the reporting process as straight-forward as possible. However, despite the limitations of this audit, the collected data has provided an overview of perinatal mortality on a national level.

There has been a positive response from most maternity units to NPEC’s mission, as well as a desire to engage with NPEC towards a national approach to perinatal data collection. All 20 hospitals/units agreed to provide NPEC with the requested data on perinatal mortality for 2008. This first-time data, although limited by the scope and variance of individual datasets and data collection procedures, reflects widespread support by clinicians towards a national perinatal mortality surveillance programme.

Looking towards the future, NPEC will remain dependant on the good will of Midwifery managers and Obstetricians who voluntarily give their time to perinatal data collection in a climate of limited resources.

5. References

The initiation of the NPEC National Advisory Group arose out of the need to establish NPEC as a national body, whose mission is founded on a national basis in the interest of Irish maternity services. NPEC Director, Prof. Greene, is keen that NPEC funding be used for the good of all women and newborn babies in the country. To this end, Prof Greene identified the need for a national advisory group, representative of all maternity units in Ireland, which would contribute to NPEC’s mission by advising and supporting NPEC. Additionally, the group would be representative of the disciplines of midwifery, neonatology, obstetrics, public health (clinical and academic) and patient representatives.

Prof Greene asked Dr. Paul Kavanagh (Specialist in Public Health Medicine, Patient Safety and Healthcare Quality Unit) of the Health Service Executive to convene and chair this group on behalf of NPEC. The idea behind the group would be that it would assist the Director and NPEC in achieving its mission on a national basis in the interest of maternity services. Subsequently, Dr. Kavanagh invited a number of representatives to join the group, taking into consideration a national spread, and both clinical and academic stakeholders. It was expected that the group would meet several times per year and would, in the future, form sub-groups to look at specific areas of the functions of NPEC.

**Members of the NPEC National Advisory Group**

Dr. Paul Kavanagh, Specialist in Public Health Medicine, HSE (Chair)
Dr. Sam Coulter-Smith, Master, Rotunda Hospital
Dr. Michael Robson, Master, National Maternity Hospital
Dr. Chris Fitzpatrick, Master, Coombe Women and Infants University Hospital
Professor Deirdre Murphy, Chair in Obstetrics, Trinity Centre for Health Sciences, St James’s Hospital
Prof. Tom Clarke, Consultant Neonatologist, Rotunda Hospital
Dr. Michael Brassil, Consultant Obstetrician and Gynaecologist, Portiuncula Hospital
Dr. Eleanor Molloy, Consultant Neonatologist, National Maternity Hospital
Geraldine Keohane, Director of Midwifery, Cork University Maternity Hospital
Dr. Heather Langan, Consultant Obstetrician and Gynaecologist, Sligo General Hospital
Dr. Con Sreenan, Consultant Neonatologist, Limerick Regional Hospital
Dr. Declan Devane, Senior Lecturer, National University of Ireland, Galway
Ann Keating, Midwife, Clinical Midwife Manager 3, Our Lady of Lourdes Hospital
Dr. Edward O’Donnell, Consultant Obstetrician and Gynaecologist, Waterford Regional Hospital
Connie McDonagh, Clinical Midwife Manager 3, St. Luke’s General Hospital
Dr. Mary O’Mahony, Specialist in Public Health Medicine, HSE
Advisory Group Role and Responsibilities

1. The role of the advisory group is to advise and support NPEC in the achievement of its defined mission and objective through:

   1.1. Advising on its content and implementation of its strategy, business plan, and relevant policies and procedures
   1.2. Ensuring that it reflects the views of service users and health care professionals
   1.3. Taking into account best practice on monitoring the outcome of maternity care nationally and internationally

2. In particular, the Group will provide NPEC with advice and support on issues in relation to access to NPEC data and secondary research.

3. Support and facilitate consultation and information exchange between the NPEC and key stakeholders in support of the Centre’s mission and objective.

4. The Chair to the Advisory Group will endeavour to secure consensus decisions. Where this is not possible, the chair will present views to the Director of NPEC who will take the ultimate decision on the issue.

See Appendix B for minutes of the inaugural meeting of the NPEC National Advisory Group – 20th November 2009.
A note from Prof. Mona Lydon-Rochelle:
Since joining NPEC, I have had the opportunity to observe Ireland’s own unique maternity care services, character and traditions that distinguish it from the United States. As NPEC’s epidemiologist, wherever I go the conversation most often focuses on the health of mothers and infants. In recent years, many countries throughout Europe have invested extensively in their research capacity to study pregnancy-associated outcomes at the population-based level and proudly Ireland is no exception.

Each year approximately 70,000 women give birth in Ireland, and minimizing morbidity and mortality among these women and their infants is an important clinical and public health priority. To that end, here at NPEC we are building collaborations with international universities and research centres so that we can better build research capacity, competency and creativity here at home.

Historically, hospital-specific perinatal studies have successfully been used in Ireland to identify local morbidity and mortality trends and risk factors for adverse perinatal health outcomes. Studies based on local data have the advantage of identifying important health problems and providing potential answers to questions at a local context. However, they cannot substitute for studies based on national data for identifying national trends and patterns of the major perinatal health problems of Ireland’s mothers and infants, or assessing the causes of these problems. In Ireland, the patterns and practices of clinical care during childbirth hospitalization are virtually unknown at the national level. Furthermore, the morbidity, complication rates and procedures associated with childbirth have not been evaluated, particularly with regards to maternal and newborn outcomes. Recent epidemiologic studies in Ireland have provided useful information using Hospital In-Patient Enquiry (HIPE) data for investigating non-childbirth related morbidity and mortality. Yet, while the HIPE data contain important information on childbirth discharges from all 19 public maternity hospitals in Ireland, no published studies to date have been conducted examining childbirth using HIPE data. Similarly, Ireland’s birth registration data use has been limited to descriptive statistics.

NPEC’s mission is to establish and implement national monitoring of the health of mothers and infants before, during and after childbirth, in order to identify and promote research investigation of health outcomes. Accurate assessment of adverse health outcomes for mothers and infants can be accomplished in various ways, including introducing electronic check-box birth registration forms; collecting confidential enquiry data that record case reports on all maternal deaths; implementing national electronic standardized maternity charts; universal publishing of hospital
level reports; and performing data linkages with birth registration data. Of these methods, the most feasible and cost-effective method for identifying a wide range of childbirth-associated morbidity and mortality at a national level is a data linkage of birth registration to HIPE data.

Advances in data linkages have been a particular feature of important perinatal epidemiological studies in Finland, Norway, Sweden, Denmark, Scotland, Australia and the USA. Specifically, the ability of countries to link birth records to other databases provides unique research opportunities with resultant findings to improve the delivery of care to mothers and infants. Firstly, study findings have identified better information on maternal and neonatal adverse outcomes than birth registration alone. Secondly, studies in which birth registration and hospital discharge data are matched, is a widely used design for assessment of additional covariates and innovative record linkages. Notably, the conduct of more advanced analyses by using multiple data sources for longitudinal linkages to hospital readmissions, maternal and foetal death certificates, and subsequent births is of particular usefulness. Thirdly, one of the principal justifications for large, maternally-linked cohort studies is the ability to conduct sub-studies on selected participants and uncommon events.

In 2007, Ireland had an all time increase in the caesarean delivery rate (26%), and preterm delivery (6.1%). To date, no large population-level study findings are available to provide the basis for examining trends over time, advancing clinical practice or informing public health decision-making specific to hospital childbirth. Notwithstanding, the lack of a merged dataset with “perfect” sensitivity and specificity, these linkages represent a true advance over reliance on HIPE or birth registration alone for conducting perinatal epidemiologic research. Given the common occurrence of birth hospitalization, it is something of an anomaly that no large epidemiological studies using both birth registration and hospital discharge has been conducted. Remarkably, no population-based studies on the health of mothers and infants have been undertaken at the national level in the Republic of Ireland.

In conclusion, we aim to advance knowledge regarding the occurrence and distribution of maternal and infant health in Ireland by developing a strong and diverse research program, characterized by outstanding research collaborations. Furthermore, we plan to build depth, breadth and creativity in our research capacity at NPEC and to provide professional service in epidemiology by having NPEC work with all maternity hospitals, as well as national and local health agencies and other organizations to conduct collaborative research and to provide technical assistance. Finally, we aim to educate and train professionals in epidemiology, through training at the masters, doctoral and post-doctoral levels.

Mona T. Lydon-Rochelle, Perinatal Epidemiologist
### Finance

**Income**

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<td>Total Income</td>
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**Expenditure**

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**Income less expenditure- 2009**

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<td>€103,898.25</td>
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Note: Pay costs for the Centre are under budget in 2009, due to 4 new personnel taking up their posts in mid-year (replacing 2 previous personnel). A further staff member was hired in December 2009, due to start in January 2010. NPEC intends to recruit a further 2 posts in 2010.

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Appendix A: Minutes of Perinatal Mortality Group Meetings in 2009

1st Meeting of Perinatal Mortality Group – 23rd April 2009, Cork University Maternity Hospital

The group held its inaugural meeting on 23rd April 2009, at which Prof. Greene introduced NPEC and his reasons for developing the Perinatal Mortality Group. It was agreed at this meeting that the membership of the group adequately represents the regions of Ireland.

The group agreed to start small, in terms of what data is collected, in order to make the notification process as simple as possible for staff involved. As this surveillance programme will be confidential, it is intended that hospitals will provide anonymised data. It was agreed that collecting data on perinatal mortality should ideally be via a clinical link person from each maternity unit/hospital. NPEC’s midwife co-ordinator, Edel Manning, will liaise with units regarding the collection of data. The difficulties of collecting data in small units, especially those that do not have computerised record systems, were discussed.

The meeting highlighted the lack of shared information between Obstetrics and Paediatrics/Neonatal in some hospitals: this could potentially lead to problems such as double counting, missing cases, etc.

Definitions from various bodies were discussed and it was accepted that a 500g cut-off be used for all still births. However, babies born alive even if <500g creates a dilemma. If >22 weeks and born alive, they need to be recorded if possible.

Prof Greene introduced the Terms of Reference for the group, and some changes to the Terms were agreed upon. It was agreed that the group would meet twice annually, and that meeting venues would alternate between Cork and Dublin.

2nd Meeting of Perinatal Mortality Group – 8th October 2009, Cork University Maternity Hospital

The 2nd meeting of the PMG began with NPEC’s midwife co-ordinator, Edel Manning, presenting perinatal statistics from 17 Irish maternity units for 2008.

The coding system used for classification of perinatal deaths, i.e. the Wigglesworth Classification, was discussed. It was agreed by members of the Group that there was some ambiguity within this classification, and that the system for coding perinatal deaths should be clarified for the purposes of NPEC data collection.
It was highlighted that in many cases of perinatal mortality, post-mortems were not undertaken or encouraged when clinical observations were made at delivery: this occurred particularly where a nuchal cord was identified. The lack of post-mortems, leading to possible misreporting of the causes of perinatal death, could potentially skew the findings of the Group.

Another problem, which affects NPEC data, concerns the transfer of Neonates from one hospital to another: specifically, the birth hospital often does not receive any feedback regarding the outcome of the baby after the transfer. The provision of feedback regarding late neonatal death or infant death to the obstetric hospital is not universal practise. The potential to add a datapoint to the NPEC registry concerning the transfer of Neonates from one hospital to another was highlighted.

The value of coroners’ reports of perinatal mortalities was also discussed and it was agreed that building relationships with coroners’ offices would be beneficial for NPEC data collection.
Appendix B: Minutes of the NPEC National Advisory Group Meeting – 20th November 2009

The initial meeting was held on 20th November 2009 at Dr. Steeven’s Hospital, Dublin. The meeting was opened by Dr. Paul Kavanagh and followed by a presentation from Prof. Greene on the objectives and history of NPEC. This was followed by a presentation from Prof. Mona Lydon-Rochelle on her perinatal epidemiology work in NPEC and her plans to establish an Irish Childbirth Registry.

NPEC Data Collection
A number of issues were subsequently discussed at the meeting, including the matter of NPEC’s data collection from Irish maternity units. Prof Greene confirmed that whilst NPEC’s remit is to carry out epidemiological research on data, a large amount of dedicated time had to be put into collection of that data. It was highlighted that many of the smaller maternity units in the country do not have electronic data systems in place and NPEC needs to be realistic about the challenges of gathering data from such smaller units. Edel Manning, NPEC’s midwife co-ordinator, highlighted that there is a huge variance in midwifery resources amongst maternity units and that gaining access to their data is often dependant on whether or not the unit in question has a midwife dedicated to data collection and clinical audit. Edel is continuing with her work to access and collect maternity data from the country’s maternity units.

Access to NPEC Data
NPEC collects and holds data from all Irish maternity units. In the context of requests to NPEC for data for research purposes, the issue of who should have access to that data, and whose role it is to oversee and regulate the release of data, was discussed. Whilst NPEC is a national unit, it sits within the governance of UCC, and for this reason, it was suggested that there should be representation by clinicians, colleges, hospitals and stakeholders other than UCC, with regard to the release of NPEC data. The group discussed the importance of having transparency in the process of data requisition and access, and the need to have a formal policy on data access in place. It was subsequently decided, and agreed by Prof. Greene, that a subgroup of the NPEC National Advisory Group would formulate a policy for access to NPEC data.

The group was termed the Data Access Sub-Group and is made up of the following members: Harry Comber (Chair), Sam Coulter-Smith, Michael Robson, Deirdre Murphy, Geraldine Gaffney, Eleanor Molloy, Declane Devane and Con Sreenan. The Sub-Group was scheduled to meet and revert to the Advisory Group with a data access policy.
National Advisory Group Terms of Reference
There was a general discussion on the Terms of Reference and a number of amendments were agreed upon. The Group will endeavour to meet twice annually.