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Maternity Hospitals According to HSE Region and Hospital Size
Introduction and Commentary

Welcome to the 2012 Annual Report from the National Perinatal Epidemiology Centre (NPEC). At a time when the Irish maternity services have come under intense scrutiny, we at the NPEC, endeavour to provide these services with a facility to undertake in-depth reviews of its own medical practices, through monitoring outcomes and regular audit. Additionally, we are committed to expanding research expertise in maternal and perinatal health.

This is the first year in which the Centre will release separate reports containing the results of two of its audit projects. National perinatal mortality data for 2011 will be published in the NPEC Perinatal Mortality Report 2011, due for release in April 2013. Similarly, the results of the first year of our national audit of maternal morbidity will be released in 2013.

In 2012, the Centre invested time and resources in strengthening its data collection processes. The development of three on-line databases, namely on perinatal mortality, maternal morbidity and, in conjunction with the Self-Employed Community Midwives (SECMs), a perinatal surveillance database for home birth deliveries, was initiated. It is anticipated that the introduction of data collection using on-line databases will allow the NPEC to access data in a timelier manner. Furthermore, data from on-line databases can assist in individual hospital audit and could potentially improve planning and care in the maternity services. Health information systems, such as these databases, are an essential tool in modern healthcare systems to facilitate research using a standardised dataset at both hospital and national level.

We continued to investigate pertinent research topics in maternal and perinatal health: in 2012, the Women’s Health Study, focusing on pregnancy loss, and the Pregnancy Risk Assessment Monitoring System (PRAMS), a large population based cohort study, were rolled out. We focussed attention on the risks and benefits of Caesarean section by hosting a study day on Vaginal Birth After Caesarean Section (VBAC), in addition to sponsoring a Ph.D. project on the impact of Caesarean section in subsequent pregnancies.

It would be impossible for us to undertake our projects, both in audit and research, without the collaboration of the many midwives, obstetricians, academics, neonatologists and administrators who have supported and collaborated with the Centre; and similarly, the patients who have kindly agreed to participate in our large cohort research studies. On behalf of the NPEC, I extend my sincere thanks and appreciation to all for their time and contribution. Whilst it is not a statutory requirement to report data to the NPEC, in 2012, all of the country’s 20 maternity units voluntarily provided obstetric and neonatal data to the Centre, thereby demonstrating their commitment to improving the service and outcomes for their patients.

I thank the members of the Perinatal Mortality Group, the Maternal Morbidity Group and the NPEC National Advisory Group for their support and valuable contributions. Lastly, I thank the staff of the NPEC for their hard work and dedication to the mission. The Centre continues to prosper amongst the good will granted us. On behalf of all the staff at the NPEC, we look forward to a challenging and fruitful 2013.

Richard A. Greene, Director
# NPEC Staff and Contact Information

## Staff details

<table>
<thead>
<tr>
<th>Staff Member</th>
<th>Position</th>
<th>Telephone</th>
<th>Email</th>
</tr>
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<tbody>
<tr>
<td>Prof. Richard Greene</td>
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</tr>
</tbody>
</table>

For general queries, please e-mail npec@ucc.ie.

L-R: Ms. Sinéad O’Neill, Ms. Linda O’Keeffe, Prof. Richard Greene, Dr. Leanne O’ Connor, Ms. Sarah Meaney, Ms. Edel Manning, Ms. Linda Drummond, Mr. Christopher Fawsitt.
2012 NPEC Internships

In the summer of 2012, two students interned at the NPEC: Máire McCarthy, a University College Cork Masters in Public Health student, contributed to the NPEC maternal morbidity audit, whilst, Nathalie Forgeard, a medical student from the Université Paris VII - Diderot, conducted research on Vaginal Birth After Caesarean Section (VBAC) in Ireland.

2012 Funding Awards

Jennifer Lutomski, an epidemiologist with the NPEC, was a recipient of the 2012 Health Research Board Cochrane Review Training Fellowship. Jennifer will be conducting a review entitled, “Expert Systems for Fetal Assessment” for the Cochrane Pregnancy and Childbirth Group. In brief, this review will evaluate if intelligence software can improve the interpretability of cardiotocography (CTG) traces to reduce the incidence of neonatal complications and unnecessary operative delivery. Her review supervisor is Professor Declan Devane (Chair of Midwifery, National University of Ireland, Galway), who is an Associate Editor with the Cochrane Pregnancy and Childbirth Group and has a keen interest in fetal assessment.
Current Projects at the NPEC

Perinatal Mortality Surveillance in Ireland

In 2009, the NPEC established the Perinatal Mortality Group to develop a national audit of perinatal mortality in Ireland from a clinical viewpoint. The fundamental aim of this programme is to improve Irish perinatal outcomes through the provision of clinical key epidemiological evidence and clinical audit data. Whilst developing a comprehensive clinical dataset on perinatal mortality, the NPEC in collaboration with the Perinatal Mortality Group has collected and analysed perinatal mortality data from Irish maternity units since 2008. Membership of the Group is listed in Appendix A.

National perinatal mortality results from 2011 will be published in the NPEC Perinatal Mortality Report 2011, which is due to be released in April 2013. Unit-specific reports containing 2011 anonymised perinatal mortality rates will also be provided to contributing units for comparative purposes in 2013.

To date, submission of perinatal mortality data to the NPEC is through completion of the Perinatal Death Notification Form, in paper format. In 2012, development of an on-line perinatal mortality database was initiated. The database will facilitate data collection by allowing units to access the database through the NPEC website and completion of the Perinatal Death Notification Form in electronic format, in addition to streamlining data analysis by NPEC staff. Roll-out of the on-line Perinatal Death Notification Form will begin in 2013, for collection of 2012 data.

Maternal Morbidity Surveillance in Ireland

In 2010, the NPEC set up a multidisciplinary specialist Maternal Morbidity Group (Appendix B) with the specific aims of establishing a confidential audit on all cases of severe maternal morbidity in Ireland and to perform a detailed assessment of major obstetric haemorrhage. Collection of anonymised data from Irish maternity units commenced in January 2011 using two standardised notification forms:

- The Severe Maternal Morbidity Notification Form
- Major Obstetric Haemorrhage Case Assessment Form

Results for the first year of the national maternal morbidity audit will be published in the NPEC Maternal Morbidity Report 2011, which is due for release in April 2013. Development of the NPEC maternal morbidity database began in 2012, and is anticipated to facilitate the on-line completion of the Maternal Morbidity Notification Form and submission of data to the NPEC.

Home Births in Ireland

The NPEC is collaborating with the Self Employed Community Midwives (SECM) in the development of a data collection tool to record clinical outcomes on planned home births in Ireland. The data collection tool allows SECMs to evaluate their own practice which is central to the future development of a safe and high quality home births service. The benefits of this collaboration include transparency of practice and care; comparability to other SECM practices, both nationally and internationally; comparability to other models of maternity care for ‘low risk’ pregnant women in Ireland, as well as the facilitation of ‘choice’ for pregnant women in Ireland, by contributing towards a body of evidence-based knowledge.
Collection of home births data began in 2012: it is collected and submitted to the NPEC by designated regional SECMs using an electronic form. The NPEC is currently developing an on-line database which is due for completion in early 2013.

**Pregnancy Risk Assessment Monitoring System (PRAMS)**

Each year, approximately 75,000 women give birth in Ireland. Yet, to date, there are major gaps in population-based studies characterising the experiences of women before, during and after pregnancy in Ireland. To address these gaps, the NPEC collects data using the Pregnancy Risk Assessment Monitoring System (PRAMS). The programme was originally developed by the US Centre for Disease Control and Prevention in 1987.

The primary aim of the PRAMS is to improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity and maternal morbidity.

A PRAMS pilot study was undertaken in February 2012. A number of modifications were subsequently made to the study instrument and protocol. In October 2012, a larger PRAMS study was rolled out, involving 1,200 women having had recent live births at Cork University Maternity Hospital; it is anticipated some of the initial findings from the PRAMS study will be available in late 2013.

**Models of Maternity Care**

Across the country, high quality, individualised maternity care is offered to all women, regardless of income or other socio-economic factors. Depending on geographic location, women may also be offered a wide range of maternity care services in addition to traditional consultant-led care. These include midwifery-led care, Domiciliary In and Out of Hospital (DOMINO) care, or home birth care. However, very little is known about women’s preferences for maternity care. The NPEC, in collaboration with the School of Economics in UCC, is investigating women’s preferences for these alternative models of maternity care. This study will inform policy practice, clinical managers and health care providers on the model of care women prefer and why. Moreover, given an increased interest at policy level to expand maternity services across the country,
such as midwifery-led care and the DOMINO scheme, the results of the study will help policymakers evaluate whether an expansion of maternity services would reflect an efficient use of resources in Ireland.

**Women’s Health Study**

Pregnancy loss is the most common adverse outcome in pregnancy, with 15-20% of all pregnancies ending in miscarriage. The majority of early pregnancy losses are attributed to unknown causes, and the aetiology of early and late miscarriage remains poorly understood. The Women’s Health Study is a cohort study which aims to examine a number of possible risk factors for miscarriage, focusing particularly on lifestyle behaviour characteristics: these characteristics include diet, exercise, alcohol, smoking and drug-taking behaviours.

Eligible women have been enrolled in the study from March 2012 from before or at the time of their routine 10-14 week scan. Data are collected using the Women’s Health Study booklet. The participants are subsequently followed up to assess the status of the pregnancy at 20 weeks.

The study is led by Dr. Keelin O’Donoghue of the Department of Obstetrics and Gynaecology, University College Cork in collaboration with the NPEC, and is currently underway in Cork University Maternity Hospital. It is hoped that the findings from this study will identify risk factors for miscarriage which will improve pregnancy outcome in the future.

**The Impact of Caesarean Section on Pregnancy Outcome in Subsequent Delivery**

With Caesarean section rates at the highest ever recorded (currently more than one in four of all babies born in Ireland) and the long-term risks and benefits of this operative delivery disputed, particularly in the subsequent delivery, this research uses population-based registry data as part of a collaboration with Aarhus University, Denmark. Using a cohort of more than 800,000 women who have given birth between January 1982 and December 2010, the hypothesis that a previous Caesarean section may lead to an increased risk of subsequent ectopic pregnancy, spontaneous miscarriage, stillbirth or longer between-pregnancy intervals compared to a previous vaginal delivery is being investigated. It is hoped that the findings will better inform women’s decisions regarding mode of delivery, especially among first-time mothers, as well as practicing clinicians and policymakers.
Qualitative Research - Pregnancy Loss; Mode of Delivery; and Aspects of Intra-Partum Care

In 2012, the NPEC initiated a number of qualitative research studies, focusing on parents’ experiences and perceptions of the Irish maternity services; as well as aspects of parental decision-making after experiencing an early pregnancy loss or perinatal death. A number of qualitative methodologies are utilized, involving parents in one-to-one interviews or in focus groups. The qualitative data are analysed to identify key themes and the meaning of these phenomena in a social context. It is hoped that the knowledge gained from parents’ personal accounts will help inform future clinical practice. These projects are outlined below.

Experiences of miscarriage
There is significant psychological morbidity associated with any pregnancy loss, and it can have long term effects on both the physical and emotional wellbeing of parents. The NPEC, in collaboration with Dr. Keelin O’Donoghue of the UCC Department of Obstetrics and Gynaecology and Dr. Stephen Gallagher of the Department of Psychology, University of Limerick, is currently conducting studies on men’s and women’s experiences of miscarriage. It is hoped that the information garnered from these parents’ experiences will help develop initiatives which will inform and support parents who experience such a loss in the future.

Parents perceptions and understanding of autopsy
Given the extensive impact of perinatal death, it is imperative to understand the underlying causes. Often clinicians cannot attribute late pregnancy loss to any particular cause, thereby underscoring the importance of autopsy to identify underlying factors leading to stillbirth. However, autopsy rates have declined in recent years. A study, in association with Dr. Keelin O’Donoghue and Dr. Stephen Gallagher, is underway in the NPEC which aims to gain insight from parents who have experienced stillbirth and who were asked to provide consent for an autopsy to be conducted. From this study, we aim to understand what the perception of autopsy is, as well as the decision-making processes around autopsy.

Mode of Delivery
In 2011, the National Institute for Health and Clinical Excellence (NICE) published updated guidelines on caesarean section and stated that women should be offered evidence-based information, to help them make a decision regarding their mode of delivery. The guidelines also advocated that women’s views and concerns are an integral part of the decision-making process. These guidelines are likely to have an impact on Irish hospital practice. Therefore, the NPEC, in collaboration with Dr. Keelin O’Donoghue and Dr. Stephen Gallagher, has initiated a study which aims to explore the experiences of women in relation to choosing a mode of delivery.

Women’s preferences for different aspects of intra-partum care
The publication of the NICE guidelines has highlighted that the views and concerns of women are integral to intra-partum care. Depending on the maternity unit, certain aspects of care may vary across units, such as access to pain relief, availability of medical staff, homeliness of the room, access to neonatal services, amongst other aspects of care. The relative importance of these different aspects of intra-partum care to women is not widely known in Ireland. The NPEC, in collaboration with the School of Economics in UCC, is currently examining women’s preferences for intra-partum care, knowledge of which may inform the practices of health care providers and clinical managers. If the results of this study are recognized at hospital level, the maternity services may be aligned accordingly to reflect women’s preferences.
Continuing Professional Development

Vaginal Birth After Caesarean Section (VBAC) Study Day, 20th January 2012

The NPEC hosted a Vaginal Birth After Caesarean Section (VBAC) Study Day on 20th January at the Radisson Blu Royal Hotel, Golden Lane, Dublin to stimulate discussion regarding VBAC in Ireland. The event was well attended, with 225 multidisciplinary delegates from across the country.

The speakers on the day included Prof. Richard Greene, Director of the NPEC; Ms. Jennifer Lutomski, Epidemiologist at the NPEC; Prof. Deirdre Murphy, Head of Obstetrics and Gynaecology, Trinity College Dublin; Prof. Declan Devane, Chair of Midwifery, National University of Ireland, Galway; Dr. Dorthe Fuglenes, University of Oslo, Norway; Prof. Michael Turner, National Clinical Director in Obstetrics & Gynaecology, HSE; Ms. Patricia Healy, Midwifery PhD Student, National University of Ireland Galway; Dr. Michael Geary, Consultant Obstetrician and Gynaecologist, Rotunda Hospital and Dr. Shane Higgins, Consultant Obstetrician and Gynaecologist, National Maternity Hospital.

The presentations gave rise to constructive discussions: and the day was concluded by a debate entitled “VBAC – The Risks Outweigh the Benefits”, a motion which was defeated following a show of hands by the audience.

Speakers at the VBAC Study Day:
L-R: Dr. Michael Geary, Prof. Richard Greene, Prof. Michael Turner, Prof. Declan Devane, Mr. Christopher Fawsitt, Dr. Michael O'Dowd, Ms. Jennifer Lutomski, Ms. Patricia Healy, Prof. Deirdre Murphy, Dr. Dorthe Fuglenes, Dr. Shane Higgins.
Attending the VBAC Study Day:
Prof. Robbie Harrison, Dr. Cathy Allen, Dr. Liz Dunne, Dr Cathy Burke.

Attending the VBAC Study Day:
Ms. Mary Jeffery and Ms. Mary Quaid.

To access a presentation(s) from the professional development day, please contact Leanne O’Connor (leanne.oconnor@ucc.ie).
Publications and Conferences, 2008-2012

**Bold print** signifies NPEC staff member or intern.

**Peer-reviewed manuscripts**


Other publications


Conferences


30. **Lydon-Rochelle, MT**. "What are the interventions and maternal morbidities during childbirth hospitalisation in Ireland?" Ireland’s Annual Joint Midwifery Conference. Armagh, Northern Ireland. Oct 2010. (Key Note Speaker)


**Centre reports**


**Data briefs**

National Perinatal Epidemiology Centre, Data Brief. August 2012; No. 5
Cost-effectiveness analysis comparing trial of labour after previous Caesarean versus elective repeat Caesarean delivery

National Perinatal Epidemiology Centre, Data Brief. June 2012 2012; No. 4
Severe maternal morbidity during childbirth hospitalisation: A comparative analysis between Ireland and Australia

National Perinatal Epidemiology Centre, Data Brief. February 2012; No. 3
Increasing trends in atonic postpartum haemorrhage in Ireland

National Perinatal Epidemiology Centre, Data Brief. May 2011; No. 2
Caesarean Section Study Day 2011

National Perinatal Epidemiology Centre, Data Brief. March 2011; No. 1
Maternal morbidity in Ireland: A national perspective using Hospital In-Patient Enquiry data

If you would like to be added to the distribution list for the NPEC Data Brief, please send a request to npec@ucc.ie.
Collaborators

The NPEC welcomes collaboration with various disciplines both nationally and internationally, and the Centre has been working with institutions across the country.

Some of the most important work I have done this year has been in collaboration with the NPEC. I have been fortunate to work with Ms. Jennifer Lutomski and Prof. Richard Greene on important clinical issues including post-partum haemorrhage and vaginal birth after caesarean section. In addition to the important clinical questions being addressed by the NPEC, I am excited about the methodological questions being addressed and see this as an important area for future collaboration. Here's to another successful year!

-Professor Declan Devane, Chair of Midwifery, National University of Ireland, Galway

I am delighted to have undertaken collaborative work with the NPEC in 2012. I have a number of postgraduate and undergraduate students working with NPEC staff in the area of perinatal research.

Using qualitative research methods we are examining parents' experiences of different aspects of pregnancy and birth, and more recently have focused on the area of pregnancy loss. Few studies have until now addressed the lived experience of miscarriage or stillbirth, and there is little qualitative research showing how parents understand and make sense of pregnancy loss. We aim to exploit these different investigative approaches for real patient benefit and hope this will also improve understanding and increase awareness amongst healthcare professionals.

-Dr. Keelin O'Donoghue, Consultant Obstetrician and Senior Lecturer, Department of Obstetrics and Gynaecology, University College Cork

As a Lecturer in Midwifery and member of the national advisory group on severe maternal morbidity, I have had the pleasure of working closely with Professor Greene and the team in the NPEC and admire the work being done to improve the health and well-being of women and babies nationally.

As a PhD student, I have sought advice from epidemiologists and others within the team and found them to be generous with their time and advice. The NPEC is a marvellous resource to have in Ireland and their annual conference has become an important educational event for all professionals working within the maternity services.

-Ms. Deirdre Daly, Lecturer in Midwifery, Trinity College Dublin
## Budget Accounts

### Income

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**Income Less Expenditure 2012** €22,991

## 2012 NPEC Staffing

### Staff Complement

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<td>Ph.D. Students</td>
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Appendix A: Membership of the Perinatal Mortality Group

Ms Bridget Boyd, Assistant Director of Midwifery, Coombe Women & Infants University Hospital
Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE

Dr. David Corcoran, Consultant Paediatrician, Rotunda Hospital
Nominated by the Faculty of Paediatrics

Dr. Patricia Crowley, Consultant Obstetrician & Gynaecologist, Coombe Women & Infants University Hospital
Nominated by the Institute of Obstetricians & Gynaecologists, RCPI

Dr. Elizabeth Dunn, Consultant Obstetrician & Gynaecologist, Wexford General Hospital
Nominated by the Institute of Obstetricians & Gynaecologists, RCPI

Dr. Siobhan Gormally, Consultant Paediatrician, Our Lady of Lourdes Hospital
Nominated the Faculty of Paediatrics, RCPI

Ms. Oonagh McDermott, Assistant Director of Midwifery, Sligo General Hospital
Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE

Dr. Eoghan Mooney, Consultant Pathologist, National Maternity Hospital
Nominated by the Faculty of Pathology, RCPI

Ms. May Quirke, Assistant Director of Midwifery, Tralee General Hospital
Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE
(Ms. Maudie Creagh, Tralee General Hospital, Nominated by May Quirke to attend in her absence)

Ms. Ann Rath, Clinical Midwife Manager III, National Maternity Hospital
Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE

Dr. John Slevin, Consultant Obstetrician & Gynaecologist, Midwestern Region Maternity Hospital Limerick
Nominated by the Institute of Obstetricians & Gynaecologists, RCPI

Dr. Anne Twomey, Consultant Paediatrician, National Maternity Hospital
Nominated by the Faculty of Paediatrics, RCPI

Ms. Patricia Williamson, Assistant Director of Midwifery, Rotunda Hospital
Nominated by Elizabeth Adams, Deputy Nursing Services Director, HSE

Prof. Richard Greene, Consultant Obstetrician & Gynaecologist, Cork University Maternity Hospital
Chair, Director of the National Perinatal Epidemiology Centre

Ms. Edel Manning, Research Midwife, National Perinatal Epidemiology Centre
Perinatal Mortality Project Manager, National Perinatal Epidemiology Centre

Ms. Jennifer Lutomski, Epidemiologist, National Perinatal Epidemiology Centre
National Perinatal Epidemiology Centre

Ms. Sarah Meaney, Health Promotion Research Officer, National Perinatal Epidemiology Centre
National Perinatal Epidemiology Centre
Appendix B: Membership of the Maternal Morbidity Group

**Dr. Bridgette Byrne**, Consultant Obstetrician & Gynaecologist, Coombe Women & Infants University Hospital
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Ms. Deirdre Daly**, Lecturer in Midwifery, Trinity College Dublin
*Nominated by Deputy Nursing Services Director, HSE*

**Dr. Declan Devane**, Chair of Midwifery, National University of Ireland, Galway
*Nominated by Deputy Nursing Services Director, HSE*

**Dr. Michael Geary**, Consultant Obstetrician & Gynaecologist, Rotunda Hospital
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Dr. Miriam Harnett**, Consultant Anaesthetist, Cork University Hospital
*Nominated by the Irish College of Anaesthetists*

**Ms. Ita Kinsella**, Clinical Midwife Manager II, Midland Regional Hospital, Portlaoise
*Nominated by Deputy Nursing Services Director, HSE*

**Ms. Janet Murphy**, Advanced Midwife Practitioner, Waterford Regional Maternity Hospital
*Nominated by Deputy Nursing Services Director, HSE*

**Dr. Ray O’Sullivan**, Consultant Obstetrician & Gynaecologist, St. Luke’s Hospital, Kilkenny
*Nominated by the Institute of Obstetricians & Gynaecologists, RCPI*

**Prof. Richard Greene**, Consultant Obstetrician & Gynaecologist, Cork University Maternity Hospital
*Chair, Director of the National Perinatal Epidemiology Centre*

**Ms. Edel Manning**, Research Midwife, National Perinatal Epidemiology Centre
*Severe Maternal Morbidity Project Manager, National Perinatal Epidemiology Centre*

**Ms. Jennifer Lutomski**, Epidemiologist, National Perinatal Epidemiology Centre
*National Perinatal Epidemiology Centre*
Appendix C: NPEC National Advisory Group Members

The NPEC National Advisory Group was established to advocate and assist with the development of the Centre on a National basis. Specifically, the role of the Group is to support the NPEC in the achievement of its mission by advising on the NPEC’s work strategy, business plan and relevant policies. To ensure the work of the Centre reflects the views of service users and health care professionals, the National Advisory Group is multidisciplinary and includes representatives from midwifery, neonatology, obstetrics and public health who are invested in improving maternal and neonatal services in Ireland.

Chair: Professor Michael Turner, Professor of Obstetrics and Gynaecology, UCD Centre for Human Reproduction, Coombe Women and Infants University Hospital

Dr. Sam Coulter-Smith, Master, Rotunda Hospital

Dr. Michael Robson, Consultant Obstetrician and Gynaecologist, 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 Hospital

Professor Tom Clarke, Consultant Neonatologist, Rotunda Hospital

Dr. Michael Brassil, Consultant Obstetrician and Gynaecologist, Portiuncula Hospital

Dr. Eleanor Molloy, Consultant Neonatologist, National Maternity Hospital

Ms. Geraldine Keohane, Director of Midwifery, Cork University Maternity Hospital

Dr. Heather Langan, Consultant Obstetrician and Gynaecologist, Sligo General Hospital

Professor Declan Devane, Chair of Midwifery, National University of Ireland, Galway

Dr. Mary O'Mahony, Specialist in Public Health Medicine, HSE

Ms. Connie McDonagh, Clinical Midwife Manager 3, St. Luke’s General Hospital

Ms. Ann Keating, Clinical Midwife Manager 3, Our Lady of Lourdes Hospital

Dr. Geraldine Gaffney, Senior Lecturer, National University of Ireland, Galway

Dr. Edward O’Donnell, Consultant Obstetrician and Gynaecologist, Waterford Regional Hospital

Dr. Rhona Mahony, Master, National Maternity Hospital and Ms. Marie Cregan, University College Cork (Patient Representative) were formally nominated to the Group, and Dr. Michael Robson invited to the Chair, in December 2012.
Appendix D: NPEC Anonymised Data Access Policy

National Perinatal Epidemiology Centre

Policy on Access to Anonymised Data for Research Purposes

Version 1.0, Valid as of April 2010

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   Form A: Confidentiality/Non-Disclosure Agreement

1. Introduction

The National Perinatal Epidemiology Centre (NPEC) encourages the use of its data for research purposes. In supplying data, the NPEC must comply with its obligations of confidentiality under the Data Protection Acts (1988 and 2003). The use of the data by the applicant must also be consistent with the Data Protection Acts.

This policy document defines who can have access to the NPEC’s data; the procedures to be followed in submitting a request for data; and the limitations placed on the data which is released.

This policy refers only to the release of anonymised data: a separate policy will be developed for sensitive data

2. Policy

It is policy of the NPEC that all requests for data for research purposes be considered by a committee, termed the Data Access Committee. All requests for access to data for research purposes will be handled equitably, through the same process, whether the request comes from the NPEC internally or from an external source. It is the policy of the NPEC to have transparency in the decision-making process; in this regard, details of projects for which access has been granted will be published on the NPEC website.

Requests will be considered only from individuals affiliated with an education, healthcare or other research institution. A meeting or consultation with the requester may be required if there are any questions or reservations about the release of data.
3. Responsibilities

**NPEC Director**

The Director is the custodian of all NPEC data. The Director, or his/her appointee, will serve as a member of the Data Access Committee that evaluates requests for data. The Director, or his/her appointee, will consult with the Committee regarding all decisions on data access.

The Director is also responsible for the formulation and implementation of adopted policies relating to data access; and for staff/requester compliance with these policies.

**Data Access Committee**

The Committee will be responsible for evaluating all requests for data. The Committee will evaluate requests based on a first-come, first-served basis. In the unlikely event that more than one request to use similar data comes before the Committee at the same time, the Committee will initiate discussion on potential collaboration between the requesters. Should such collaboration not be possible, the Committee will make a recommendation as to which party should have the requested data, based on the merits and potential benefits of the proposed study, and the feasibility of the study methodology in achieving its stated goals and objectives. Following Committee meetings, the NPEC will publish, on its website, a register of approved projects, for the information of prospective researchers.

The Committee will be comprised of a sub-group of the NPEC National Advisory Group and will represent all relevant parties, including clinical and non-clinical researchers in obstetrics, paediatrics, midwifery and other relevant disciplines/professions. It will provide advice to the Director of the NPEC on matters concerning data access by researchers.

The Committee will meet as often as necessary to deal with requests for data, but at least bi-annually. The Committee may recommend that a request for access be accepted, rejected or accepted pending specified changes.

**NPEC Staff**

The NPEC staff will confirm receipt of all requests for data access. The staff is responsible for ensuring that all requests meet the relevant criteria, and for processing requests expeditiously. Requests which do not meet the criteria will be returned with suggestions for change.

**The Requester**

The requester is responsible for addressing any ethical issues regarding his/her use of NPEC data. The requester should also acknowledge the NPEC as the provider of data in any publication or presentation.

4. Procedures for Submitting a Request for Data

Requests for data must be made using a standard data request form and the attached ‘Confidentiality/Non-Disclosure Agreement’ must be signed (Form A).
Requests must be submitted to the NPEC electronically, and must be submitted at least two weeks prior to the next-occurring meeting of the Data Access Committee, the dates of which will be published on the NPEC website.

5. Criteria for Release of Data

All requests for data access must be approved by the Data Access Committee.

Once a request has been approved and the data provided, the data must be used by the requester within three months of the date of release of data. Requesters will be obliged to submit to NPEC evidence of data analysis and usage, if requested by NPEC. Should this evidence not be forthcoming or be deemed unsatisfactory, NPEC retains the right to allow other researchers who have requested the same/similar data access to it for their own research purposes.

In certain circumstances, it will be necessary to charge a fee for the release of data in order to cover the costs to NPEC of preparing the data: such circumstances include when the amount of data processing is extensive or in cases where the data are requested for commercial purposes.

6. Data Release Format

Data will be released in electronic format. A full description of the data file may be supplied to the user prior to a formal request.

7. Limitations on Usage of Data

When submitting a request for data, the applicant must undertake:

- to use the data only for the purposes specified in the request;
- not to transmit or provide the data to anyone not mentioned in the data request;
- not to use the data, or allow it to be used, in any way which is in breach of the Data Protection Acts (1988 and 2003);
- not to attempt to identify any individual from the data;
- to delete or destroy the data at a specified time, and to inform NPEC that this has been done (N.B. The NPEC should make a note of this date at the time of granting a request and set up an automatic reminder);
- to acknowledge NPEC as the source of the data, e.g. “based on data provided by the National Perinatal Epidemiology Centre, Ireland” (or similar agreed acknowledgement) in any publication (print or online, limited circulation or otherwise);
- not to present in the results of analyses or other reports, or in releases of information concerning such reports, any information that might identify a patient.

8. Appeal Process

The NPEC provides a mechanism for appeal of data access decisions. Appeals must be made in writing to the Director of the NPEC within 6 weeks of the date of the NPEC decision letter. The reasons for the appeal must be clearly stated. A copy of the original request for data access should also be attached.
The Director will subsequently bring the appeal request to the Data Access Committee, which will make the decision. The requester will be notified of the decision as soon as possible, but should be made aware that this is dependent on the convening of the Committee.

9. Inquiries from Press and Public

The NPEC staff responses to inquiries by the press and public will be based only on information available in published documents or on the NPEC website.
Form A: Confidentiality/Non-Disclosure Agreement for data provided by the National Perinatal Epidemiology Centre

I have read and understand the conditions under which this data is being provided by the National Perinatal Epidemiology Centre.

I undertake:

- to use the data only for the purposes specified in the request;
- not to transmit or provide the data to anyone not mentioned in the data request;
- not to use the data, or allow it to be used, in any way which is in breach of the Data Protection Acts (1988 and 2003);
- not to attempt to identify any individual from the data;
- to delete or destroy the data at a specified time, and to inform the National Perinatal Epidemiology Centre that this has been done;
- to acknowledge the NPEC as the source of the data, e.g. “based on data provided by the National Perinatal Epidemiology Centre, Ireland” (or similar agreed acknowledgement) in any publication (print or online, limited circulation or otherwise);
- not to present in the results of analyses or other reports, or in releases of information concerning such reports, any information that might identify a patient shall be.

Name: _______________________________________

Signature: ___________________________________ Date: ______________________