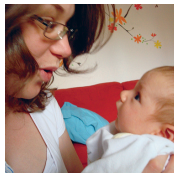
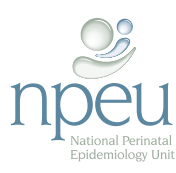
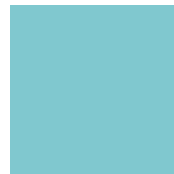
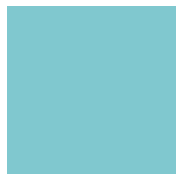
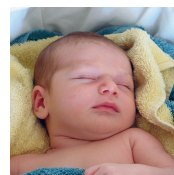


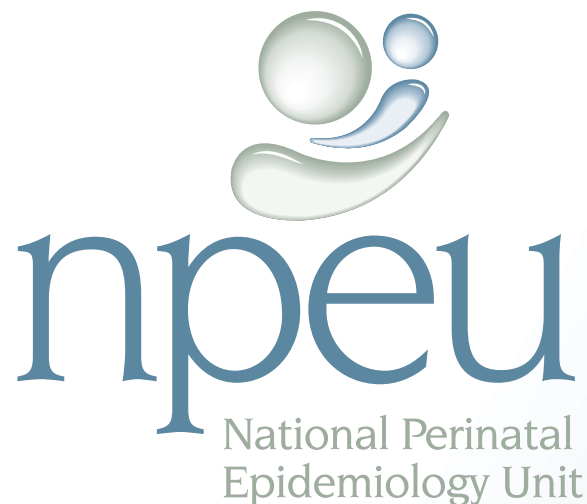


Delivered with care:
a national survey of women's
experience of maternity care 2010



National Perinatal Epidemiology Unit

Annual Report 2010



Front Cover

Illustration of the 'Delivered with Care' report of the findings of the National Maternity Survey 2010: Women's experience of Maternity Care. Details of the project can be found on "National Maternity Survey 2010: Women's Experience of Maternity Care" on page 15 and the full report can be downloaded from our website: <https://www.npeu.ox.ac.uk/delivered-with-care>

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Introduction

Welcome to the 2010 Annual Report for the National Perinatal Epidemiology Unit. The most important news we received during 2010 was that the Department of Health (England) are continuing to provide resources to the NPEU. The DH have supported the NPEU since its inception in 1978, but in 2009, following a strategic review of their support for policy research, they invited competitive applications for a new range of Policy Research Units. One of these was in Maternal Health and Care and we are delighted to say that the Policy Research Unit for Maternal Health and Care (PRU-MHC) was awarded to the NPEU in 2010 (www.npeu.ox.ac.uk/prumhc). This support runs from January 2011 until December 2015.

The other major piece of news for 2010 is that I announced my resignation as Director of the NPEU, effective from 1 April 2011, to become the Director of the Institute for Women's Health at University College London. Dr Jenny Kurinczuk, Deputy Director of the NPEU, was appointed to become Director of the NPEU from 1 April 2011. I will continue to have a role at the NPEU as Co-Director of the PRU-MHC alongside Jenny.

2010 also saw the departure of another longstanding member of the NPEU, Dr Stavros Petrou. Stavros joined the Unit in 1997 as a Health Economist who rapidly became the Unit's Senior Health Economist with a broad range of interests and a prodigious output. Stavros has left to become Professor of Health Economics at the University of Warwick, within the Warwick Clinical Trials Unit and we wish him every success for the future.

The NPEU continues to be successful and productive in terms of its income and output. In 2010 a total of 48 peer reviewed papers were published by NPEU along with 'Delivered with Care' the results of the 2010 national maternity survey and a range of outputs from the Inequalities in Infant Mortality project, including evidence maps, briefing papers and systematic reviews. All of these are available on our website at www.npeu.ox.ac.uk/infant-mortality. We received funding for a range of new UKOSS studies (www.npeu.ox.ac.uk/ukoss), as well as funding from the MRC (£2.5m) to follow up the CORONIS trial (also MRC funded). CORONIS is a complex randomised controlled trial (a 2x2x2x2x2

fractional factorial design) to assess the effects of a range of different surgical techniques at the time of caesarean section on short term outcomes for the mother and baby. By the end of 2010, when recruitment stopped, almost 16,000 women were included from centres in Ghana, Kenya, Sudan, India, Pakistan, Argentina and Chile. This new MRC funding will allow us to follow these women up for three years after their participation in CORONIS to assess the longer term impact of these surgical techniques on their general and reproductive health. 2010 also saw the start of the NIHR funded Near-miss Surveillance Programme (UKNeS) which is designed to develop and implement a comprehensive national programme of surveillance and study of near-miss maternal morbidities which will complement the work of the confidential enquiry into maternal deaths and improve outcomes for women and their babies (www.npeu.ox.ac.uk/uknes).

Although I am very sorry to be leaving the NPEU after nearly 17 years, the Unit is in an excellent position to move forward with an exciting and important programme of work with a team of excellent researchers. Jenny Kurinczuk will make a superb Director and the Unit will continue the long history of research excellence in the perinatal field. I wish everyone in the Unit the very best for the future.



NPEU Director 2002-2011:
Professor Peter Brocklehurst

New Director appointed at NPEU

1st April 2011

Dr Jenny Kurinczuk was appointed as Director of the National Perinatal Epidemiology Unit from the 1st April 2011 becoming the fifth Director of the NPEU since its inception in 1978. She is also Co-director of the Policy Research Unit in Maternal Health and Care, funded by the Department of Health and recently awarded to the NPEU team (www.npeu.ox.ac.uk/prumhc).

Jenny joined the NPEU in October 2003 as Consultant Clinical Epidemiologist and was promoted to Deputy Director of the Unit and Reader in Perinatal Epidemiology in 2008. Her research expertise lies particularly in the areas of the causes and consequences of neonatal encephalopathy, cerebral palsy and congenital anomalies, and the health outcomes for children born following assisted conception. She is also involved in leading national studies of near miss maternal morbidity (www.npeu.ox.ac.uk/uknes) and the evaluation of paediatric surgical interventions for congenital anomalies (www.npeu.ox.ac.uk/baps-cass).



NPEU Director from 1st April 2011:
Dr Jenny Kurinczuk

Contact Details

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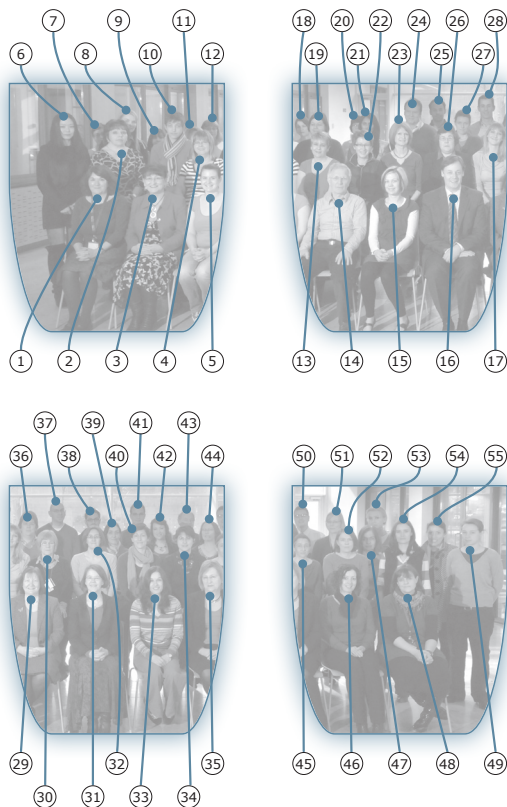
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OX3 7LF

For individual staff contact details
and email addresses, please go to:
www.npeu.ox.ac.uk/staff

NPEU Staff



- | | |
|------------------------|----------------------------|
| 1. Lynn Lynch | 29. Jenny Kurinczuk |
| 2. Angela Garrett | 30. Tricia Boyd |
| 3. Linda Mottram | 31. Marian Knight |
| 4. Lyn Pilcher | 32. Rachel Rowe |
| 5. Shannon Armstrong | 33. Nina Armstrong |
| 6. Rui Zhao | 34. Mara Violato |
| 7. Patsy Spark | 35. Sue Bellenger |
| 8. Emma Haines | 36. Ursula Bowler |
| 9. Barbara Farrell | 37. James Griffiths |
| 10. Suzanne Williams | 38. Luke Blount |
| 11. Louise Linsell | 39. Oya Eddama |
| 12. Pauline Rushby | 40. Shan Rich |
| 13. Karen Lindsay | 41. Andy Kirk |
| 14. Bob Gatten | 42. Liz Schroeder |
| 15. Sarah Chamberlain | 43. Ron Gray |
| 16. Peter Brocklehurst | 44. Jane Forrester-Barker |
| 17. Anna Hobson | 45. Ann Kennedy |
| 18. Aimee Crowshaw | 46. Maria Quigley |
| 19. Lydia Saroglou | 47. Stella Khenia |
| 20. Mandy Slark | 48. Sarah Lawson |
| 21. Nishma Patel | 49. Alex Bellenger |
| 22. Katie Lean | 50. Ed Juszcak |
| 23. Brenda Strohm | 51. Gry Poulsen |
| 24. Edward Gosden | 52. Cath Rounding |
| 25. Paul Heal | 53. Dominika Misztela |
| 26. Lynne Roberts | 54. Kate Fitzpatrick |
| 27. Marta Nowicki | 55. Colleen Acosta-Nielsen |
| 28. David Puddicombe | |

Missing

Vicki Barber
Clara Bowyer
Claire Carson
Helen Davenport
Sara Edwards
Pollyanna Hardy
Jane Henderson

Jennifer Hollowell
Denise Jennings
Yvonne Kenworthy
Andy King
Gwyneth Lewis
Kayleigh Morgan
Laura Oakley

Maggie Redshaw
Dimitrios Rovithis
Anne Smith
Dana Sumilo
Julia Sutton
Melanie Workman

Website

www.npeu.ox.ac.uk

The NPEU website has steadily grown more popular each month as the Unit continues to grow. There are hundreds of individual visitors each day and new features and facilities continue to be added to provide a better experience for all.

- The website receives more than 1,500 individual visitors each week, viewing over 7,000 pages between them.
- The top three most popular areas of our site are:

1. "What We Do - by Topic" (www.npeu.ox.ac.uk/topics)
2. "UKOSS" (www.npeu.ox.ac.uk/ukoss)
3. "Birthplace" (www.npeu.ox.ac.uk/birthplace)

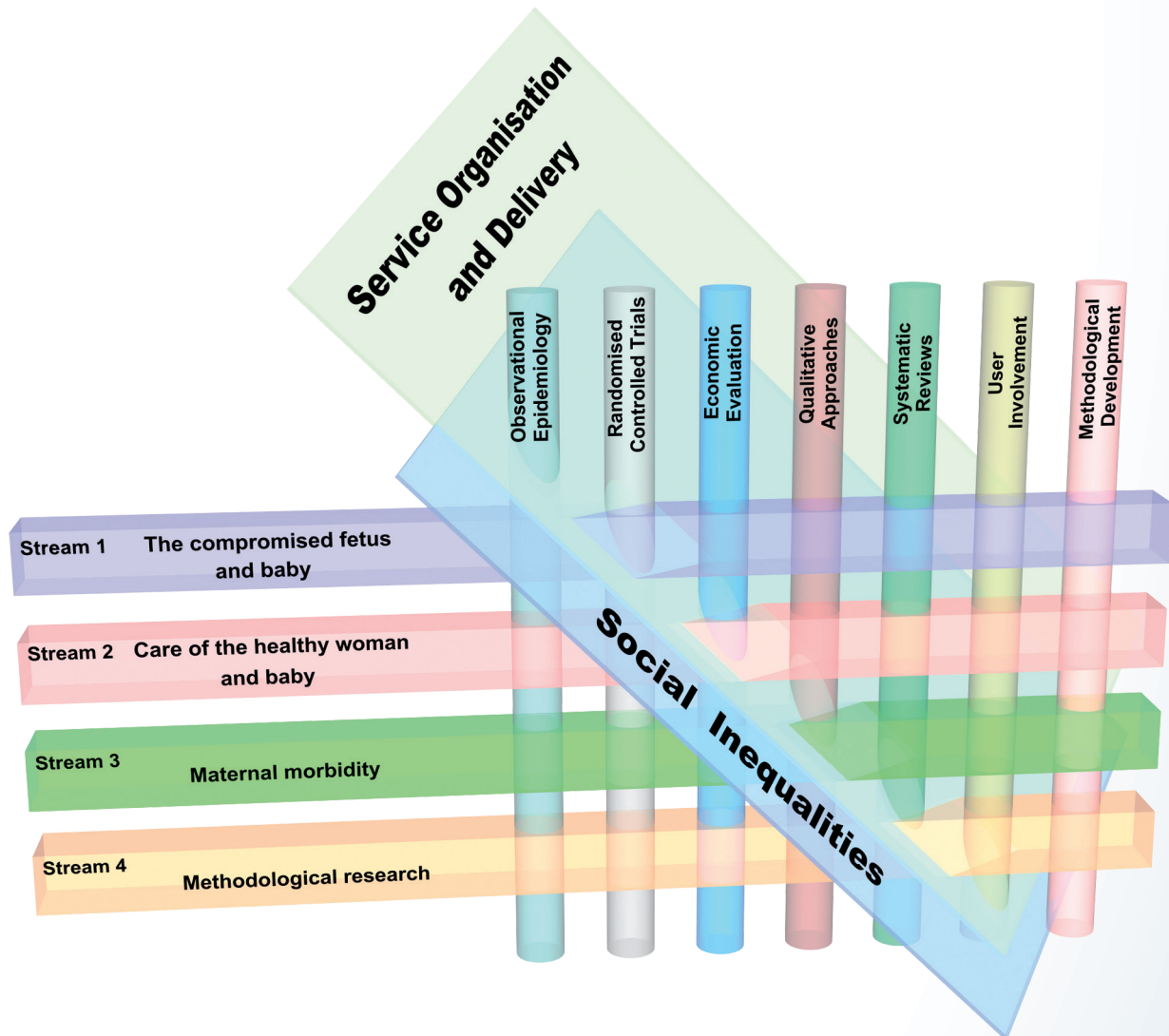
The screenshot displays several key pages from the PiPS trial website:

- Centre Details:** Lists participating hospitals such as Barnet Hospital, Croydon University Hospital, Homerton University Hospital, and John Radcliffe Hospital, along with their respective clinical leads and contact information.
- Recruitment Summary:** A table showing monthly recruitment figures for various centres over a 6-month period.
- Participating Centres:** A map showing the geographical distribution of participating hospitals across the UK.
- News:** A section titled "NEWS: Dr Jenny Kuruczak to become the new Director of the NPEU" dated 24 Mar 2011.

Recruiting centre	Total	Apr 11	Mar 11	Feb 11	Jan 11	Dec 10	Nov 10
Homerton University Hospital	63	8	8	9	7	10	1
Medway Maritime Hospital	4	4					
Newham University Hospital	2	2					
Queen's Hospital, Romford	8	1	2		2	1	1
Southeast University Hospital	1		1				
St Peter's Hospital, Chertsey	12	3		6	3		
St Thomas' Hospital, London	10	4	3	3	5	3	
The Royal London Hospital	13	2		4	1		
Whipps Cross Hospital	10	1	3	1	2		
Whittington Hospital	1	1					
William Harvey Hospital, Ashford	11	2	2	2	5		
Total	143	22	22	27	22	16	4

Some useful pages from PiPS trial website

Programme of Work



Introduction

The NPEU programme of work for the period 2009 to 2011 is described in this section of the report. The programme of work is conceptualised and illustrated above using the framework of four streams of work with two cross-cutting themes and the rods denoting the different research methodologies used. A summary of all the work in progress and work completed during 2009 and 2010 is given in the following two tables which separate work

in progress, listed in the first table, from completed studies which are given in the second table. Following the summary tables and to avoid the repetition from year to year we have included the full details of only new projects which started in 2010. These are described after the summary table under the headings of the four streams of work. Further information can be found on our website: www.npeu.ox.ac.uk

Programme of Work – Ongoing Studies

NPEU Table of Work Key

NPEU contact: Most projects involve an NPEU team and often outside collaborators. The postscript (a) means that the grant holder or chief investigator for the project is from outside the NPEU.

The initials of the NPEU researchers are used in the table for brevity and represent the chief investigator or the researcher who is taking the lead for the project at the NPEU:

PB	Peter Brocklehurst	EJ	Ed Juszczak	RR	Rachel Rowe
TB	Tricia Boyd	MK	Marian Knight	LS	Liz Schroeder
OE	Oya Eddama	JK	Jenny Kurinczuk	BS	Brenda Strohm
BF	Barbara Farrell	SP	Stavros Petrou*	MV	Mara Violato
RG	Ron Gray	MQ	Maria Quigley		
JH	Jennifer Hollowell	MR	Maggie Redshaw		

* Stavros Petrou left the Unit in August 2010.

Stream 1: The compromised fetus and baby	Duration	NPEU Contact
1.1 Neonatal encephalopathy, cerebral palsy and other childhood impairments		
Reaching consensus on the definition of neonatal encephalopathy for surveillance purposes	2005-11	JK
Secondary analysis of Western Australian case control data to further investigate the relationship between intrapartum events, neonatal encephalopathy and cerebral palsy	2005-12	JK
NEST trial – Whole body cooling for neonates undergoing extracorporeal membrane oxygenation (ECMO)	2005-12	EJ(a)
INFANT trial – A multi-centre randomised controlled trial of an intelligent system to support decision making in the management of labour using the cardiotocogram	2009-14	PB
Economic evaluation alongside INFANT trial – cost-effectiveness of an intelligent decision support system	2009-14	PB
Economic evaluation alongside TOBY trial – cost-effectiveness of total body cooling	2006-13	OE
UK TOBY Cooling Register: register of the use of moderate hypothermia in neonates	2007-11	BS
TOBY Children Study – School age outcomes following a newborn cooling trial	2009-13	BS(a)
TOBY Xenon: Neuroprotective effects of hypothermia combined with inhaled xenon following perinatal asphyxia	2009-12	EJ

Stream 1: The compromised fetus and baby	Duration	NPEU Contact
1.2 Child health outcomes following assisted reproductive technologies (ART) and related fertility issues		
International collaborative work using record linkage methods to investigate the risks of cerebral palsy, intellectual disability, hospitalisation and congenital anomalies associated with ART	2003-11	JK(a)
A population-based study of the effect of infertility and its treatment on child health and development	2008-11	MQ
1.3 Congenital anomalies		
CAROBB – Monitoring rates of congenital anomalies for surveillance purposes	2003-11	TB
1.4 Preterm birth		
Parents’ experience of care following admission of their infant to a neonatal unit	2006-11	MR
PROGRAMS trial – GM-CSF for sepsis prophylaxis in preterm growth-restricted babies	2001-12	PB(a)
BOOST-II UK trial – targeting oxygen saturation levels in preterm babies	2006-12	EJ(a)
PiPS – Probiotics in preterm babies study	2009-13	PB(a)
I2S2 – Iodine supplementation trial – iodine supplementation for premature babies	2009-14	PB
Economic evaluation alongside PROGRAMS trial – the cost-effectiveness of GM-CSF for sepsis prophylaxis in preterm growth-restricted babies	2001-10	EJ
A population-based study of the health and developmental consequences of preterm birth	2009-11	MQ
ePrime – Evaluation of MR imaging to predict neurodevelopmental impairment in preterm infants	2009-14	MR(a)
1.5 Fetal and infant effects of rare disorders of pregnancy (see Stream 3)		
Development of the British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)	2006-12	MK
BAPS-CASS – Before, during and after birth – how does care affect the future health prospects of infants with congenital diaphragmatic hernia?	2009-12	JK
1.6 Infant mortality		
Inequalities in Infant Mortality work programme – follow-on study	2010-11	JH

Stream 2: Care of the healthy woman, baby and child	Duration	NPEU Contact
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2.1 Attitudes towards pregnancy and childbirth

Nothing currently in progress under this heading – see table of completed studies for work in this area

2.2 Recent users' views and experience of maternity care

Nothing currently in progress under this heading – see table of completed studies for work in this area

2.3 Antenatal screening

Nothing currently in progress under this heading – see table of completed studies for work in this area

2.4 Minor problems in pregnancy

Nothing currently in progress under this heading – see table of completed studies for work in this area

2.5 Care in labour and delivery

CORONIS Trial – fractional factorial trial of caesarean section surgical techniques in developing countries	2006-11	BF
Changes in maternity care over time	2007-11	MR
An international comparison of maternity care	2007-11	MR
BUMPES – Upright maternal position in second stage labour in women with epidural analgesia; a randomised controlled trial	2009-13	PB
Cochrane review: Psychosocial and educational interventions in latent phase or early labour for improving birth outcomes	2009-11	MQ(a)

2.6 Postnatal health and care

The impact of family income on child cognitive and behavioural outcomes in the United Kingdom	2007-11	MV
Maternal health and wellbeing in the perinatal period	2010-11	MR
Cost analysis of breastfeeding outcomes in the UK	2010-12	MQ
Improving the evidence base on breastfeeding	2011-12	MQ

2.7 Organisation of maternity care

Birthplace in England Research Programme (incorporating the Evaluation of Maternity Units in England (EMU) research programme)	2006-11	JH
Birth at Home Study	2006-11	JH

Stream 2: Care of the healthy woman, baby and child	Duration	NPEU Contact
Modelling efficiency and cost-effectiveness in maternity care in the UK	2007-11	LS
Transfer from midwifery unit to obstetric unit during labour: rates, process, outcomes and women's experience	2007-11	RR
2.8 The healthy child		
Nothing currently in progress under this heading – see table of completed studies for work in this area		
Stream 3: Maternal morbidity	Duration	NPEU Contact
3.1 Maternal mental illness		
Nothing currently in progress under this heading – see table of completed studies for work in this area		
3.2 Obesity and outcome of pregnancy		
Nothing currently in progress under this heading – see table of completed studies for work in this area		
3.3 Smoking, alcohol and drug misuse in pregnancy		
Nothing currently in progress under this heading – see table of completed studies for work in this area		
3.4 Surveillance of rare disorders of pregnancy		
Continued development of the UK Obstetric Surveillance System (UKOSS)	2005-14	MK
Surveillance of amniotic fluid embolism	2005-12	MK
Surveillance of pulmonary vascular disease	2006-12	MK
Surveillance of myocardial infarction in pregnancy	2006-11	MK
Surveillance of pregnancy in women following non-renal solid organ transplant	2007-12	MK
Surveillance of uterine rupture	2009-11	MK
Surveillance of failed intubation	2008-11	MK(a)
Surveillance of aortic dissection/dissecting aortic aneurysm in pregnancy	2009-12	MK
Surveillance of pituitary tumours in pregnancy	2009-12	MK(a)
Surveillance of myeloproliferative disorders in pregnancy	2010-13	MK(a)
Before, during and after birth – how does care affect the future health prospects of infants with congenital diaphragmatic hernia? (UKOSS study)	2009-12	MK

Stream 3: Maternal morbidity	Duration	NPEU Contact
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Surveillance of sickle cell disease in pregnancy	2010-12	MK(a)
Surveillance of placenta accreta	2010-11	MK

3.5 Pregnancy complications

Factors associated with progression from near-miss maternal morbidity to fatality	2010-11	MK
Long-term follow-up of women and their infants affected by near-miss morbidity	2010-12	MK
Economic evaluation of different second-line therapies for peripartum haemorrhage	2010-11	MK
UKNeS – Beyond maternal death: Improving the quality of maternity care through national studies of 'near-miss' maternal morbidity	2010-14	MK

3.6 Pregnancy, disability and chronic illness

Nothing currently in progress under this heading – see table of completed studies for work in this area

Methodology	Duration	NPEU Contact
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4.1 Methodological developments

Dealing with childhood deaths in randomised trials (BRACELET)	2008-12	PB(a)
Health, medicines and self-care choices made by children, young people and their families: information to support decision making	2006-11	PB
Evidence into practice: evaluating a child-centred intervention for diabetes medicine management	2008-11	PB

Programme of Work – Studies Completed in 2009-10

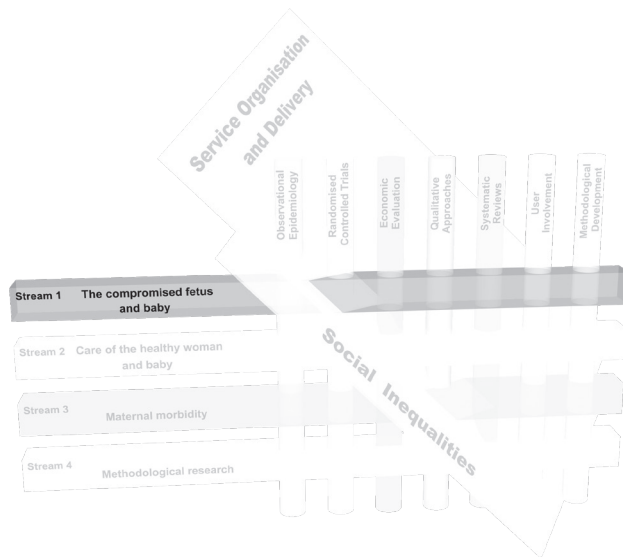
Stream 1: The compromised fetus and baby	Duration	NPEU Contact
TOBY trial – whole body cooling for babies born with neonatal encephalopathy	2002-09	BS
4Child – Monitoring rates of cerebral palsy, particularly in high risk subgroups	2003-10	JK
4Child – Monitoring rates of vision loss and hearing loss in children	2003-10	JK
UKCP Collaboration: Analysis of survival and regional variations in CP rates	2006-10	JK
Economic evaluation of progesterone for the prevention of preterm birth in twins	2005-09	OE
Economic evaluation of outpatient cervical ripening prior to induction of labour	2005-09	OE
Experience of parents of children with cerebral palsy	2007-10	JK(a)
Explore the possibility of using the HFEA database for record linkage work with regional congenital anomalies registers to further investigate the relationship between ART and risk of congenital anomalies	2006-10	JK
The effects of psychosocial stress on time to conception	2005-09	RG
Epidemiology of twinning and the effects of ART	2006-10	JK
A comparison of the early parenting experience of parents of multiples and singletons arising from natural conception and infertility treatment	2006-10	MR
Experiences, information and support needs of women and men who go through treatment for infertility and sub-fertility	2006-10	JK(a)
Clinical and cost-effectiveness of elective single embryo versus double embryo transfer policy in assisted reproduction	2008-10	JK(a)
HFEA data: Analysis of long-term trends and outcomes following ART treatment in 2006	2009-10	JK
FOCaL – Feasibility of investigating the long-term outcomes of specific congenital anomalies using congenital diaphragmatic hernia as the exemplar	2006-10	JK
EUROCAT – European Surveillance of Congenital Anomalies – Survey of prenatal diagnosis screening methods across Europe Perinatal screening for birth defects in Europe – a EUROCAT study of the impact of different national policies	2005-10	TB(a)
Cognitive and behavioural outcomes of children with an extra sex chromosome	2006-09	TB(a)

Stream 1: The compromised fetus and baby	Duration	NPEU Contact
Prenatal diagnosis and outcome of pregnancy of sex chromosome trisomies in Europe	2007-09	TB
Terminations of pregnancy at ≥ 24 weeks of gestation after prenatal diagnosis of fetal abnormality in Europe	2007-09	TB(a)
To assess information availability on prevalence and prenatal detection rates of congenital anomalies in the South East Region to allow the monitoring of screening programmes	2009-10	TB
Evaluation of prenatal diagnosis rates for major structural congenital anomalies across areas covered by BINOCAR register 2005-2006	2009-10	TB
Genetic association study of preterm birth	2006-10	RG(a)
Economic impact of preterm birth	2005-09	SP
ADEPT trial – early versus delayed enteral feeding for babies born with absent or reversed end-diastolic flow and growth restriction	2005-09	EJ
INIS trial – International Neonatal Immunotherapy Study – intravenous immunoglobulin for babies with sepsis	2000-10	BF
Economic impact of preterm birth (II)	2006-09	SP
Neonatal unit survey of communication, facilities and support for parents of preterm babies	2007-09	MR
Neonatal Taskforce Workforce: neonatal staff survey analysis	2008-09	MR
BAPS-CASS – A population-based national study of surgical outcomes of infants born with gastroschisis	2006-10	MK
BAPS-CASS – A population-based national study of surgical outcomes of infants born with oesophageal atresia	2008-10	MK
Inequalities in Infant Mortality work programme	2007-10	RG
Stream 2: Care of the healthy woman, baby and child	Duration	NPEU Contact
Analysis of trust-based data from National Maternity Surveys on women’s experience of care	2009-10	MR
National Maternity Survey 2010: Women’s Experience of Maternity Care	2010	MR
Women’s experience of support for breastfeeding	2009-10	MR
Multiple births and women’s experience of maternity care	2010	MR
Cost-effectiveness of alternative prevention and treatment strategies for GBS	2005-09	LS

Stream 2: Care of the healthy woman, baby and child	Duration	NPEU Contact
Health and wellbeing in pregnancy	2008-09	MR
ELSA trial of home versus hospital support in early labour	2004-09	MQ(a)
EUPHRATES trial – trial of blood collector bag in third stage of labour	2001-09	EJ(a)
CAESAR trial – factorial trial of caesarean section surgical techniques	2001-09	MQ
Women’s experience of caesarean section: a qualitative study	2007-09	MR
Women’s worries about labour and birth: social and ethnic differences	2007-10	MR
Women’s perceptions of maternity care	2007-10	MR
The protective effects of breastfeeding in a national UK survey	2005-09	MQ
Feeding twins, triplets and higher order multiples: a systematic review, secondary data analysis and development of evidence-based guidelines	2007-10	MQ
The effect of breastfeeding on child development	2009-10	MQ
Relationship between family income and child asthma: an econometric perspective	2006-09	RG
Birth and beyond: antenatal education and preparation for parenthood – a review of the literature and current service provision	2009	MR
Having a baby in rural areas in England	2009	MR
Stream 3: Maternal morbidity	Duration	NPEU Contact
Surveillance of extreme obesity in pregnancy	2007-10	MK
Effects of prenatal alcohol consumption and alcohol metabolising genes on child growth and neurodevelopment in the ALSPAC study	2008-10	RG
The association between alcohol consumption in pregnancy and emotional and behavioural problems in childhood	2007-09	MQ
Effect of maternal alcohol consumption on fetal growth, preterm birth, birth defects and child behaviour problems	2007-09	JK
Surveillance of fetomaternal alloimmune thrombocytopenia	2006-09	MK
Surveillance of gastroschisis	2006-09	MK
Surveillance of different methods of treating obstetric haemorrhage	2007-09	MK

Stream 3: Maternal morbidity	Duration	NPEU Contact
Surveillance of pregnancy in women with a renal transplant	2007-10	MK
Surveillance of antenatal stroke	2007-10	MK
Surveillance of multiple repeat caesarean section	2009-10	MK(a)
Surveillance of A/H1N1v influenza in pregnancy	2009-10	MK
Antenatal detection of shoulder dystocia	2007-09	MQ(a)
Methodology	Duration	NPEU Contact
Investigation of the completeness of case ascertainment by UKOSS using FMAIT as one of the candidate conditions	2006-09	MK
Investigation of the completeness of case ascertainment by UKOSS using gastroschisis as one of the candidate conditions	2006-09	MK
Comparison of different sources of incidence data for rare disorders of pregnancy	2007-10	MK
INLET trial – cluster trial of newsletters and educational supplements to centres participating in INIS trial	2006-10	EJ(a)
Programme of methodological research on economic aspects of perinatal and paediatric health care	2006-10	SP
Study of women’s preferences for alternative management methods for first trimester miscarriage (MIST)	2006-09	SP
Validation of a perceptions of care adjective check list for labour and birth	2007-09	MR
Preference-based Health Utilities Index scores for childhood conditions	2007-09	SP
Development and validation of instrument measuring aspects of the working environment in maternity and healthcare	2008-10	MR

Projects started in 2010



This further work will involve a synthesis of the relevant UK qualitative literature to identify the barriers to and facilitators of early initiation of antenatal care in socially disadvantaged and vulnerable women; and a cross-study synthesis to identify the extent to which the interventions identified in the earlier NPEU effectiveness review address barriers and facilitators relevant to disadvantaged and vulnerable women in the UK.

Contact person: Jennifer Hollowell

Funding: DH

Status of project: In progress

Stream 1: The compromised fetus and baby

1.6 Infant mortality

Inequalities in Infant Mortality work programme – follow-on study

Chief investigator:

NPEU:

Jennifer Hollowell.

Other investigators:

(Listed alphabetically)

External:

Josephine Kavanagh (*Eppi-Centre, London*).

NPEU:

Peter Brocklehurst, Ron Gray, Jenny Kurinczuk.

Other NPEU staff involved:

Laura Oakley.

This follow-on study is being undertaken to enhance the NHS relevance of the findings of a systematic review of the effectiveness of interventions to increase the early initiation of antenatal care by disadvantaged and vulnerable women, recently completed by the NPEU as part of the Inequalities in Infant Mortality project.



Stream 2: Care of the healthy woman, baby and child

2.2 Recent users' views and experience of maternity care

National Maternity Survey 2010: Women's Experience of Maternity Care

Chief investigator:

NPEU:

Maggie Redshaw.

Other investigator:

NPEU:

Katriina Heikkila.

A new national maternity survey was undertaken by the NPEU in 2010 using the same methods as were employed in 2006, the results of which were reported as 'Recorded Delivery' (2007). The target sample size was increased to 10,000 and additional sections included on fathers' involvement and on women whose babies were admitted to neonatal care. Mailings of questionnaires went out to women at three months after the birth and an online questionnaire option was made available.

The survey provides new data on fathers' engagement and updated information about choice and information, care and services from the perspective of women who had recently given birth. It looks at the experience of different groups of women and makes some comparisons across time and between women receiving care in different geographical areas of England.

Over five thousand women responded and key findings have been published on the NPEU website in a report 'Delivered with care: a national survey of women's experience of maternity care 2010'.

Contact person: Maggie Redshaw

Funding: DH

Status of project: Completed



Multiple births and women's experience of maternity care

Chief investigator:

NPEU:

Maggie Redshaw.

Other investigators:

(Listed alphabetically)

NPEU:

Jane Henderson, Jenny Kurinczuk.

Using data from the 2006 survey of women's experience of maternity care, published as 'Recorded Delivery' (2007) and from Hospital Trust based surveys of women carried out in 2007 as part of the Healthcare Commission maternity review, published as 'Towards Better Births' (2008), the aim was to describe the experience of maternity care of women having twins or triplets and to compare this with that of women having singleton births.

As little is recently known of women's experience of care during pregnancy, labour and birth and postnatally, in relation to multiple birth, these national data provide some baseline information on this important topic.

A report is being finalised for the funding organisations and this will be published on their websites. The findings will inform the development of future work on the needs and views of women and their partners experiencing multiple pregnancy and birth.

Contact person: Maggie Redshaw

Funding: DH, MBF and TAMBA

Status of project: Completed

2.6 Postnatal health and care

Maternal health and wellbeing in the perinatal period

Chief investigator:

NPEU:

Maggie Redshaw.

Other investigators:

(Listed alphabetically)

NPEU:

Reiija Klemetti, Jenny Kurinczuk.

Women report a range of physical and other symptoms in pregnancy and postnatally, ranging from backache to stress incontinence, depression and sleep problems. Understanding which groups of women experience these problems has implications for practice and will enable midwives and other health professionals to better support women during pregnancy and after childbirth.

Factors associated with women's health problems during the perinatal period are being investigated using data from studies of women's experience of maternity care (Recorded Delivery 2007). The impact of maternal age and associations between antenatal and postnatal problems, clinical factors and social and ethnic backgrounds will also be examined.

Contact person: Maggie Redshaw
Funding: DH
Status of project: In progress

Cost analysis of breastfeeding outcomes in the UK

Chief investigator:

External:
 Mary Renfrew (*University of York*).

Other investigators:

(Listed alphabetically)

External:

Rosie Dodds (*NCT*), Julie Glanville (*York Health Economics Consortium*), Felicia McCormick (*University of York*), Alison McFadden (*University of York*), Subhash Pokhrel (*Brunel University*), Paul Trueman (*Brunel University*), Anthony Williams (*St George's Hospital, London*).

NPEU:

Maria Quigley.

Despite strong evidence about the negative impact of not breastfeeding on the health and wellbeing of the infant and the mother, a cost analysis of health outcomes related to breastfeeding has never been conducted. This work will provide policy leads with evidence on the value of breastfeeding to UK health services.

Four inter-related work packages will be included in this project:

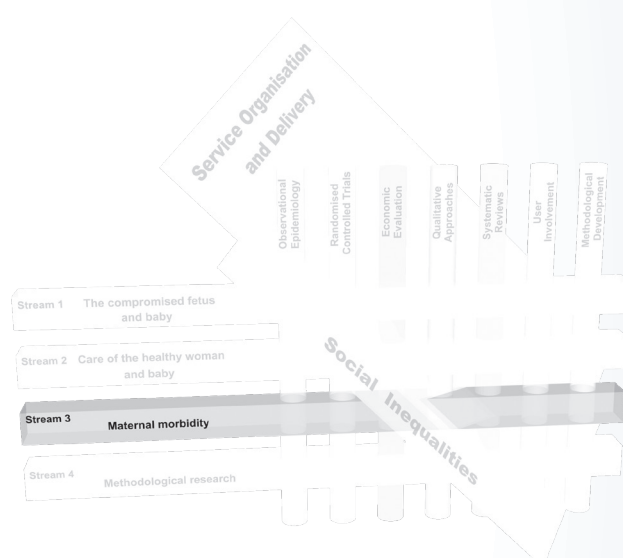
Work Package 1 - Systematic reviews.

Work Package 2 - Estimating risk ratios for health outcomes.

Work Package 3 - Economic analyses and modelling.

Work Package 4 - Methodological and policy analysis, potential impact, dissemination.

Contact person: Maria Quigley
Funding: UNICEF UK Baby Friendly Initiative
Status of project: In progress



Stream 3: Maternal morbidity

3.4 Surveillance of rare disorders of pregnancy

Surveillance of myeloproliferative disorders in pregnancy

Chief investigator:

External:
 Susan Robinson (*Guy's and St Thomas' Hospital, London*).

Other investigators:

(Listed alphabetically)

External:

Susan Bewley (*Guy's and St Thomas' Hospital, London*), Gabriella Gray (*Guy's and St Thomas' Hospital, London*), Claire Harrison (*Guy's and St Thomas' Hospital, London*), Susan Robinson (*Guy's and St Thomas' Hospital, London*).

NPEU:

Marian Knight.

Other NPEU staff involved:

(Listed alphabetically)

Carole Harris, Patsy Spark.

Myeloproliferative disorders (MPDs) are rare and generally indolent haematological cancers. Many patients are likely to be diagnosed prior to, or during, pregnancy using well defined diagnostic criteria (eg WHO). However many MPD patients also have a 'prodromal' period preceding diagnosis where symptoms and abnormal

blood counts are present but the MPD is undiagnosed. Each sub-type of MPD differs slightly with respect to laboratory and clinical features, likelihood of complications and prognosis. Many of the reports on pregnancy outcome represent the experience of single specialist institutions, and are therefore likely to be biased. MPDs in pregnancy are thus under-researched, our understanding of them is poor and any interventions used in current clinical practice are rarely based on robust evidence.

By prospectively collecting data on known and occult MPDs in pregnancy using the UK Obstetric Surveillance System this study will provide valuable information about the epidemiology and complications of MPD in pregnancy with a minimal risk of significant bias.

Contact person: Marian Knight
Funding: Guy's and St Thomas' Hospital Charity
Status of project: In progress



Surveillance of sickle cell disease in pregnancy

Chief investigator:

External:

Jo Howard (*Guy's and St Thomas' Hospital, London*).

Other investigators:

External:

Eugene Oteng-Ntim (*Guy's and St Thomas' Hospital, London*).

NPEU:

Marian Knight.

Other NPEU staff involved:

(Listed alphabetically)

Carole Harris, Patsy Spark.

Sickle cell disease (SCD) is the most common genetic disorder worldwide and in the UK, with 12-15,000 affected individuals in the UK alone. The term SCD refers to homozygous HbSS (inheritance of two HbS genes) and also to the compound heterozygotes (co-inheritance of one HbS gene and another

abnormal haemoglobin gene, for example, haemoglobin (Hb) C, HbE, HbD, or the B thalassaemia gene). SCD is a multi-organ disorder characterised by intermittent episodes of severe pain which may require hospital admission for treatment, and other complications including chest disease, pulmonary hypertension, stroke, retinopathy, renal failure, avascular necrosis and leg ulcers.

There are some historical data, mostly from outside the UK, showing a high incidence of maternal and fetal complications in SCD, but no contemporary or recent prospective data from the UK.

The numbers of deliveries in women with SCD has increased markedly over recent years, from 25-30 deliveries across the whole UK in the 1970s, to the current situation of approximately 150-250 deliveries per year. SCD has great geographical variability across the UK, with the greatest numbers of deliveries occurring in London or other major conurbations such as Manchester and Birmingham, but with small numbers of deliveries distributed across the rest of the UK.

There is a lack of consensus about the best management strategies for optimum care of these women, although it is clear that good committed obstetric care is of vital importance. The lack of knowledge about incidence of pregnancy in affected women, makes it difficult to plan services, to plan optimal care, or in the long term to plan further trials into best practice.

This study will collect data about the incidence across the UK and identify patterns of management practice.

Contact person: Marian Knight
Funding: Guy's and St Thomas' Hospital Charity

Status of project: In progress

Surveillance of placenta accreta

Chief investigator:

NPEU:

Marian Knight.

Other investigators:

(Listed alphabetically)

External:

Susan Sellers (*St Michael's Hospital, Bristol*).

NPEU:

Peter Brocklehurst, Jenny Kurinczuk.

Other NPEU staff involved:

(Listed alphabetically)

Jane Forrester-Barker, Carole Harris, Patsy Spark.

Placenta accreta refers to a group of uterine diseases which are characterised by an abnormally adherent placenta. This group of conditions arise from abnormal placentation where the placental chorionic villi interdigitate with the surface or invade the myometrium in the absence of an intervening decidual plate. As a consequence the pathologically adherent placenta fails to separate from the uterine wall during the third stage of labour. The associated haemorrhage can be torrential and leads to death in some cases still.

Whilst improved strategies to resuscitate women are now available placenta accreta nevertheless often necessitates emergency, life-saving management, the options for which include arterial occlusion, embolisation or ligation, or hysterectomy, the latter with its associated loss of future fertility. Where it is essential to attempt to retain fertility potential, and provided not contraindicated by the extent of haemorrhage, the intact placenta or pieces of retained placenta may be left *in situ*.

This study will determine the national incidence of placenta accreta in the UK and identify the extent to which previous caesarean section is a risk factor in this population. The study will also describe current management and outcomes. This will enable appropriate future service planning, provide accurate information which can be used when counselling women about the risks associated with caesarean section, and provide a baseline incidence against which future trends can be monitored if caesarean delivery rates continue to rise nationally.

Contact person: Marian Knight

Funding: NIHR

Status of project: In progress

3.5 Pregnancy complications

Factors associated with progression from near-miss maternal morbidity to fatality**Chief investigator:****NPEU:**

Marian Knight.

Other investigators:

(Listed alphabetically)

External:

Shona Golightly (CMACE).

NPEU:

Peter Brocklehurst, Jenny Kurinczuk.

Other NPEU staff involved:

(Listed alphabetically)

Jane Forrester-Barker, Carole Harris, Gilles Kayem, Patsy Spark.

The UK led the world in the development of confidential enquiries into maternal deaths. Since the introduction of these confidential enquiries, maternal mortality has decreased 10-fold. Data from UKOSS studies have been used to provide contextual information about underlying maternal morbidity to complement the detailed examination of mortality, but formal comparison between the information concerning women who suffered near-miss maternal morbidity and those who died from the same conditions has not been undertaken.

Information about women who died from specific causes (acute fatty liver of pregnancy, antenatal pulmonary embolism, amniotic fluid embolism, antenatal thromboembolic and haemorrhagic stroke, eclampsia) identified through the CMACE maternal deaths enquiry 2006-2008 will be compared with information on women with near-miss morbidity due to the same conditions identified through previous or current UKOSS studies of near-miss morbidity. The study will identify factors associated with fatality and survival and make recommendations for changes in practice concerning diagnosis and management in order to lead to improved outcomes for women.

Contact person: Marian Knight

Funding: NIHR and DH-PRP

Status of project: In progress

Long-term follow-up of women and their infants affected by near-miss morbidity

Chief investigator:

NPEU:

Marian Knight.

Other investigators:

(Listed alphabetically)

External:

Louise Locock (*University of Oxford*).

NPEU:

Peter Brocklehurst, Jenny Kurinczuk.

Other NPEU staff involved:

(Listed alphabetically)

Kate Fitzpatrick, Jane Forrester-Barker, Carole Harris, Patsy Spark.

Most studies of near-miss maternal morbidity, because of their retrospective hospital-based nature, report relatively short-term outcomes for women, for example, admission to intensive care or the need for hysterectomy to control haemorrhage. However, near-miss morbidities may have significant long-term impacts, both physical and psychological, on parents, their infants and other children. Exploration of these wider impacts is important to inform service provision.

This project will investigate the feasibility of long-term follow-up of affected women and their infants through both qualitative and quantitative studies of women affected by near-miss maternal morbidities.

Contact person: Marian Knight

Funding: NIHR and DH-PRP

Status of project: In progress

Economic evaluation of different second-line therapies for peripartum haemorrhage

Chief investigator:

NPEU:

Marian Knight.

Other investigators:

(Listed alphabetically)

NPEU:

Nishma Patel, Dean Regier.

Randomised controlled trials of treatments for conditions which are both rare and occur in emergency situations are particularly difficult due to issues of

informed consent as well as the large collaboration needed to conduct studies of sufficient size. Studies of effectiveness and particularly cost-effectiveness are thus rarely undertaken in this setting. National observational data, such as those obtained through UKOSS have fewer of the biases classically attributed to observational studies. This information may therefore be used to assess effectiveness of different current treatments for near-miss maternal morbidities. However, given the known variation in the use of specific interventions, national recommendations will rely on these data supplemented by economic data. For example, providing uterine artery embolisation for post-partum haemorrhage involves substantial capital outlay associated with the provision of a dedicated out-of-hours interventional radiology service.

A national observational study collecting information on health outcomes in women managed with three second-line treatments for severe peripartum haemorrhage (B-Lynch or brace sutures, factor VIIa, major vessel embolisation or ligation) has recently been completed. This project will undertake a preliminary modelling analysis to explore the use of these previously collected observational data and other data obtained through literature review to conduct an economic evaluation of these therapies.

Contact person: Marian Knight

Funding: NIHR

Status of project: In progress



UKNeS - Beyond maternal death: Improving the quality of maternity care through national studies of "near-miss" maternal morbidity

Chief investigator:

NPEU:

Marian Knight.

Other investigators:

(Listed alphabetically)

External:

Alison Burton (*Oxfordshire PCT*), Jenny Furniss (*Lay investigator*), Shona Golightly (*CMACE*), Mervi Jokinen (*Royal College of Midwives*), Louise Locock (*University of Oxford*), Susan Sellers (*St Michael's Hospital, Bristol*), James Walker (*University of Leeds*).

NPEU:

Peter Brocklehurst, Jenny Kurinczuk, Gwyneth Lewis, Maria Quigley.

Other NPEU staff involved:

(Listed alphabetically)

Jane Forrester-Barker, Carole Harris, Nishma Patel, Patsy Spark.

A comprehensive programme of study of maternal deaths has been undertaken in the UK for more than 50 years. It is now recognised that in countries such as the UK, where maternal deaths are rare, study of 'near-miss' severe maternal morbidity (defined as a severe life-threatening obstetric complication necessitating urgent medical intervention in order to prevent likely death of the mother) provides additional important information to aid disease prevention, treatment and service provision. The national collaboration of clinicians contributing to the UK Obstetric Surveillance System (UKOSS) provides a unique opportunity to undertake a programme of study of 'near-miss' severe maternal morbidity (UKNeS).

This programme will employ observational epidemiological elements with primary data collection and secondary data analysis, literature review, economic evaluation and qualitative techniques to investigate severe maternal morbidity on a national basis (see individual project descriptions).

The workstreams will describe disease incidence, risk factors, management and outcomes and investigate factors associated with disease progression from severe morbidity to death. In addition, component studies will undertake economic evaluation of different treatments for severe morbidity, explore methods for improving local learning from near-miss events and investigate women's experiences and long-term outcomes of severe maternal morbidity.

Contact person: Marian Knight

Funding: NIHR

Status of project: In progress

Incidence, risk factors and outcomes of maternal sepsis in a Scottish region over 23 years**Chief investigator:****NPEU:**

Marian Knight.

Other investigators:

(Listed alphabetically)

External:

Sohinee Bhattacharya (*University of Aberdeen*).

NPEU:

Colleen Acosta-Nielsen, Jenny Kurinczuk.

Severe sepsis is a potentially life-threatening condition, which is characterized by systemic inflammatory response syndrome (SIRS) with infection, organ dysfunction, hypoperfusion and hypotension. If untreated, this condition can rapidly progress along a continuum of severity to septicæmic shock and eventually death. Pregnant and postnatal women represent a particularly vulnerable population for developing severe sepsis due to changing physiology, biochemistry, and immune response, as well as heightened susceptibility to wound infection during delivery.

Although death as a result of pregnancy related sepsis is uncommon in the United Kingdom (UK) and other high-income countries, mortality rates have more than doubled over the last two decades in the UK and have also increased in other European countries. However, there is very little information on corresponding trends in sepsis morbidity. The aim of this study is to describe the incidence, risk factors and outcomes of maternal sepsis using data from the Aberdeen Maternal and Neonatal Databank.

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Forthcoming Papers

- 1* Petrou S, Eddama O, Mangham L. A structured review of the recent literature on the economic consequences of preterm birth. Arch Dis Child Fetal Neonat Ed.
- 2* Louis GMB, Lum KJ, Sundaram R, Chen Z, Kim S, Lynch CD, Schisterman EF, Pyper C. Stress reduces conception probabilities across the fertile window: evidence in support of relaxation. Fertil Steril.
- 3* Violato M, Petrou S, Gray R, Redshaw M. Family income and child cognitive and behavioural development in the United Kingdom: Does money matter? Health Economics.
- 4* Gray R. Commentary: Sullivan on the offspring of the female criminal alcoholic. Int J Epidemiol.
- 5* Homer CS, Kurinczuk JJ, Spark P, Brocklehurst P, Knight M. Mode of birth in women with extreme obesity. Br J Obstet Gynaecol.
- 6* Hinton L, Kurinczuk J, Ziebland S. Infertility, isolation and the internet: A qualitative interview study. Patient Educ Couns.
- 7* Kelly YJ, Sacker A, Gray R, Kelly J, Wolke D, Head J, Quigley MA. Light drinking in pregnancy: still no increased risk for socioemotional difficulties or cognitive deficits at 5 years of age? J Epidemiol Community Health.
- 8* Knight M. Studies using routine data versus specific data collection: What can we learn about the epidemiology of eclampsia and the impact of changes in management of gestational hypertensive disorders? Pregnancy Hypertension.
- 9* Henderson J, Redshaw M. Midwifery factors associated with successful breastfeeding. Child: Care, Health Dev.
- 10* Boyd P, Hauesler M, Barisic I, Loane M, Garne E, Dolk H. The EUROCAT Network: Organisation and Processes. Supplement of Birth Defects.
- 11* Bishop DVM, Jacobs PA, Lachlan K, Wellesley D, Barnicoat A, Boyd PA, Fryer A, Lachlan K, Wellesley D, Jacobs P, Middlemiss P, Smithson S, Leggett V, Nation K, Scerif G. Autism, language and communication in children with sex chromosome trisomies. Arch Dis Child.
- 12* Stavros P, Taher S, Abangma G, Eddama O, Bennett P. Cost-effectiveness analysis of prostaglandin E2 gel for induction of labour at term. Br J Obstet Gynaecol.

NPEU Advisory Committee 2010

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Royal College of Obstetricians and Gynaecologists Representative

Anthony Falconer President, Royal College of Obstetricians and Gynaecologists (from 24 September 2010)
Royal College of Obstetricians and Gynaecologists Representative

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Sources of funding

Summary of Income in 2010

Funder	Total (£)
Action Medical Research	25,799
AXA Research Fund	38,410
British Heart Foundation	16,517
BUPA Foundation	48,505
Commission for Rural Communities	7,978
Department of Health	1,917,519
European Commission	2,239
Guy's and St Thomas' Charity	21,588
Healthcare Quality Improvement Partnership (HQIP)	84,869
Heart UK	11,862
Human Fertilisation & Embryology Authority	233
Medical Research Council	1,398,590
Newlife Foundation for Disabled Children	331
NIHR	1,316,473
Obstetric Anaesthetists Association	1,573
TAMBA (Twins & Multiple Births Association)	4,170
Waltham Forest PCT	19,275
Wellbeing of Women	9,169
Wellcome Trust	48,912
Grand Total	4,974,012



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