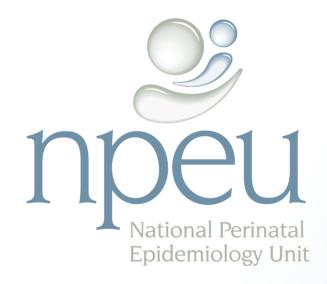


Annual Report 2007

National Perinatal Epidemiology Unit

Annual Report 2007



Front Cover

The front cover shows a graph from "Recorded delivery: a national survey of women's experience of maternity care 2006." The graph illustrates the reasons why a caesarean section was performed and compares the results with the previous study "First class delivery" which was carried out in 1995. The full study results can be found in the Unit report NPEU-89 and on the NPEU website at: http://www.npeu.ox.ac.uk/recorded-delivery

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Contents

Introduction	. 1
Website	. 3
Contact Details	. 4
Programme of Work	. 5
Introduction	. 5
Table of Work – Ongoing Studies	. 6
Table of Work – Studies Completed in 2006-07	12
Projects started in 2007	15
Stream 1: The compromised fetus and baby	15
Stream 2: Care of the healthy woman and baby	16
Stream 3: Maternal Morbidity	20
Stream 4: Methodological research	24
Publications 2006 - 2008	25
NPEU Advisory Committee 2007	33
Sources of Funding	35



Introduction

Welcome to the Annual Report for 2007. The NPEU has had another successful year, both in terms of new project funding and in publications.

On the publications front, the first papers have started to come out from UKOSS (the UK Obstetric Surveillance System). These first papers include the results of the study of peripartum hysterectomy and the study of eclampsia. UKOSS collects all cases of a range of rare conditions in pregnancy in the UK and the findings from these first two studies are fascinating and important. There were 318 peripartum hysterectomies in the UK out of a population of 780,000 births giving an incidence of 4.1 per 10,000 births. As this was a case-control study we were able to quantify the expected association with previous delivery by caesarean section and found an adjusted odds ratio of 3.5. What was less expected was that we were able to demonstrate a marked increase in the odds of more than one previous caesarean section (OR 18.6). We were also able to quantify the outcomes associated with this dramatic procedure.

The eclampsia study similarly produced fascinating results. We used the same definition of eclampsia as the last national study in 1992 and found a dramatic reduction in the incidence of eclampsia from 1992 to 2005/6 of 4.9 to 2.7 per 10,000 births. In addition, the morbidity associated with eclampsia was dramatically reduced, with the proportion of women having any severe morbidity falling from 35% in 1992 to 10% in 2005/6. It can be hypothesised that both of these improvements result, in part, from the widespread use of magnesium sulphate since the publication of the Collaborative Eclampsia Trial and the Magpie Trial.

UKOSS continues to undertake further important studies with a number of new studies started in 2007, including: therapies for postpartum haemorrhage (brace sutures, activated Factor VII and arterial embolisation/ligation); pregnancy in renal and other solid organ transplant recipients; extreme obesity (BMI greater than 50 or weight greater than 140kg); and antenatal stroke. You can keep track

of these studies by accessing the UKOSS section of the NPEU website at www.npeu.ox.ac.uk/UKOSS.

Other publications which received a lot of attention in 2007 included a new national survey of recent mothers and a systematic review of the effects of low to moderate alcohol intake in pregnancy. Recorded delivery: a national survey of women's experience of maternity care 2006, repeated and extended a similar survey conducted in 1995. We wrote to 4800 women who had given birth three months previously and asked them to complete a questionnaire about their experiences of maternity care from conception to the end of the post-natal period. We had a response rate of 63% compared with 67% in 1995. Highlights of this study include the increasing trend for women to access healthcare early in pregnancy; the number of routine antenatal visits has fallen since 1995 in line with national guidance; a fifth of women are admitted to hospital for at least one night during the antenatal period; the epidural rate in labour remains the same as in 1995 but fewer women had continuous intrapartum fetal monitoring while fewer women had a straightforward vaginal birth (23% had a caesarean section compared with 17% in 1995); and postnatal care in and out of hospital was rated less well by women than antenatal or intrapartum care. The majority of women who responded felt that staff who cared for them throughout their pregnancy were respectful, kind and supportive with a minority being wholly negative about their interactions with staff. Full details of the report can be found at www.npeu.ox.ac. uk/recorded-delivery. This work formed the basis of the Trust level surveys conducted recently by the Healthcare Commission as part of their maternity review.

The systematic review of the effects of low to moderate intake of alcohol in pregnancy also featured highly in the national press, partly because the results were unexpected to many readers. What was apparent early on in the review was that the evidence currently available was limited and sometimes of poor quality reflecting the very real difficulties of undertaking this kind of research. When

the available evidence was brought together, however, we were unable to state that low to moderate levels of alcohol intake in pregnancy were harmful. It was then fascinating to see how this piece of research was used in the development of national guidance on alcohol intake during pregnancy (DH: Pregnancy Book 2007; Antenatal care: Routine care for the healthy pregnant woman, NICE 2008 CG62).

Major new projects that were funded in 2007 included a large piece of work to help strengthen the evidence base for interventions which reduce infant mortality and narrow the health inequalities gap. More details can be found at www.npeu.ox.ac.uk/infant-mortality.

Two new large randomised controlled trials were launched in 2007. BOOST-II UK is a double masked randomised controlled trial to compare the effects of targeting arterial oxygen saturations at levels of 85-89% versus 91-95% in babies born at less than 28 weeks' gestation. The primary outcome for the trial is mortality and major disability at age 2 years (corrected for prematurity). The trial will recruit 1,200 babies from approximately 40 UK centres over four years.

CORONIS is a trial of caesarean section surgical techniques and has a complex design. It is a 2x2x2x2x2 fractional factorial trial and will recruit 15,000 women undergoing delivery by caesarean section in Argentina, Ghana, India, Kenya, Pakistan and Sudan. Details of all the ongoing trials at the NPEU can be found at www.npeu.ox.ac.uk/trials.

Finally, two members of staff were awarded fellowships in 2007. Rachel Rowe and Lizzy Schroeder will both be working on aspects of the Birthplace programme of work which is assessing the safety of different planned places of birth: home, free-standing midwifery units, alongside midwifery units and obstetric units (www. npeu.ox.ac.uk/birthplace). Rachel received an NIHR Researcher Development Award from the NCCRCD to investigate the factors affecting intrapartum transfer of women planning birth outside hospital and the outcomes associated with transfer, and Lizzy received an MRC Capacity Building Studentship to undertake economic

modelling to determine the relative costeffectiveness of different planned places of birth.





NPEU Director: Professor Peter Brocklehurst

Website

www.npeu.ox.ac.uk

The new website was launched successfully at the end of the year to a very warm reception, and is constantly being improved and enhanced. More features for both staff and visitors are gradually being added, and the pages of individual areas of work are being overhauled, providing each area with its own look and unique features.

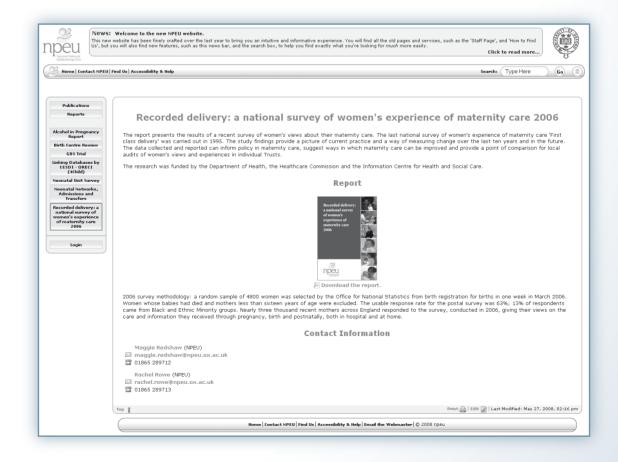
The new site makes use of modern web technologies, such as microformats (http://microformats.org/) and googlemaps (http://maps.google.co.uk/maps) and is accessible to the vast majority of web browsers and assistive technologies.

Website Statistics

 Currently, the top 8 most frequently visited areas of the website, in order, are:

- National Maternity Surveys
- o INIS
- Annual Report
- UKOSS
- TOBY
- BOOST
- N3R
- 4Child
- The most viewed staff biography page is that of Director Professor Peter Brocklehurst. His and all the NPEU staff members' biography pages are available at
 - http://www.npeu.ox.ac.uk/staff
- The most viewed item on the website to date is the pdf report 'Recorded delivery: a national survey of women's experience of maternity care 2006' (picture below) with over 82500 requests in a three month period. See it at

http://www.npeu.ox.ac.uk/recorded-delivery.



Contact Details

- Jenny Kurinczuk (Deputy Director)
- Rachel Rowe
- Peter Brocklehurst (Director)
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- 5. Marian Knight
- 6. Bob Gatten
- 7. Maggie Redshaw
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- 9. Lynne Roberts
- 10. Charlotte White
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- 13. Tricia Boyd
- 14. Chris Hockley
- 15. Jennifer Hollowell
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- 17. Brenda Strohm
- 18. Patsy Spark
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- 20. Clare Shakeshaft
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- 22. Denise Jennings
- 23. Helen Newdick
- 24. Wei-Hong Zhang
- 25. Ed Juszczak
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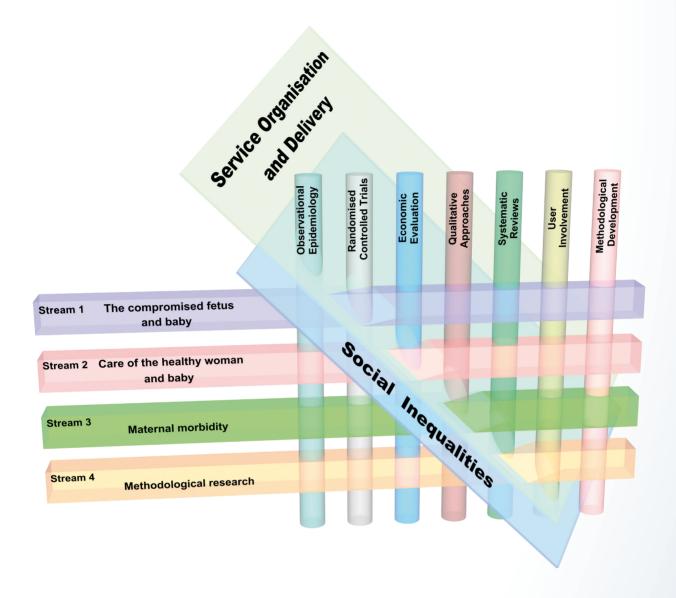


Nina Armstrong Shannon Armstrong Breidge Boyle Olayinka Chuku Oya Eddama

Carole Harris Rona McCandlish Lyn Pilcher Maria Quigley Dean Regier

Liz Schroeder Geraldine Surman Melanie White-Koning

Programme of Work



Introduction

The NPEU programme of work for the period 2006 to 2010 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 completed during 2006 and 2007 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 2007. These are described after the summary table under the headings of the four streams of work. Details of all the ongoing and recently completed projects at the NPEU are described in a longer version of the annual report which is available for download from the NPEU website at: http://www.npeu.ox.ac.uk/annualreport

Table 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:

TB	Tricia Boyd	PB	Peter Brocklehurst	RG	Ron Gray
MK	Marian Knight	JK	Jenny Kurinczuk	RM	Rona McCandlish
SP	Stavros Petrou	MQ	Maria Quigley	MR	Maggie Redshaw
RR	Rachel Rowe	LS	Liz Schroeder	GS	Geraldine Surman
MV	Mara Violato				

Stroom 1. The compressions	fotus and balan	Duration	NPEU
Stream 1: The compromised	retus and baby	Duration	contact

		Contact
1.1 Neonatal encephalopathy, cerebral palsy and othe	r childhood im	pairments
Reaching consensus on the definition of neonatal encephalopathy for surveillance purposes	2005-08	JK
Secondary analysis of Western Australian case control data to further investigate the relationship between intrapartum events, neonatal encephalopathy and cerebral palsy	2005-09	JK
TOBY trial - whole body cooling for babies born with neonatal encephalopathy	2002-08	РВ
NEST trial - whole body cooling for neonates undergoing extracorporeal membrane oxygenation (ECMO)	2005-08	PB(a)
INFANT trial - recognition and management of intrapartum fetal compromise using an intelligent decision support system	2008-12	РВ
4Child - Monitoring rates of cerebral palsy, particularly in high risk subgroups	2003-09	JK
4Child - Monitoring rates of vision loss and hearing loss in children	2003-09	JK
UKCP collaboration - Regional variations in the relationship between cerebral palsy and socio economic status	2005-08	JK(a)
UKCP collaboration - Analysis of survival, severity and regional variations in cerebral palsy rates	2006-08	GS
Economic evaluation alongside INFANT trial - cost effectiveness of an intelligent decision support system	2008-12	SP
Economic evaluation alongside TOBY trial - cost effectiveness of whole body cooling	2006-08	SP

Stream 1: The compromised fetus and baby	Duration	NPEU contact
Experiences of parents of children with cerebral palsy	2007-09	JK(a)
1.2 Child health outcomes following assisted reproduct & related fertility issues	ctive technolog	gies (ART)
International collaborative work using record linkage methods to investigate the risks of cerebral palsy, intellectual disability, hospitalisation and congenital anomalies associated with assisted reproductive technologies	2002-09	JK(a)
Survey of fertility, reproductive choices and future plans	2006-08	JK(a)
The effects of psychosocial stress on time to conception	2005-08	RG
Epidemiology of twinning and the effects of ART	2006-08	JK
A comparison of the early parenting experience of parents of multiples and singletons arising from natural conception and infertility treatment	2006-08	MR
A population based study of the effect of infertility and its treatment on child health and development	2008-10	MQ
Experiences, information and support needs of women and men who go through treatment for infertility and subfertility	2006-09	JK(a)
1.3 Congenital anomalies		
CAROBB - Developing a system for monitoring rates of congenital anomalies for surveillance and research purposes	2003-09	ТВ
FOCaL - feasibility of investigating the long-term outcomes of specific congenital anomalies using congenital diaphragmatic hernia as the examplar	2007-08	JK
Survey of prenatal diagnosis screening methods across Europe	2005-08	ТВ
Congenital hydrocephalus: a population based study of prevalence and outcome	2005-08	TB(a)
Cognitive and behavioural outcomes of chidren with an extra sex chromosome	2006-09	TB(a)
1.4 Preterm birth		
Economic evaluation of progesterone for the prevention of preterm birth in twins	2005-08	SP
Genetic association study of preterm birth	2006-10	RG(a)

Stream 1: The compromised fetus and baby	Duration	NPEU contact	
Parents' experience of care following admission of their infant to a neonatal unit	2005-08	MR	
ADEPT trial - early versus delayed enteral feeding for babies born with absent or reversed end diastolic flow and growth restriction	2005-09	РВ	
INIS trial - International Neonatal Immunotherapy Study - intravenous immunoglobulin for babies with sepsis	2000-10	РВ	
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	2006-11	РВ	
PREFER trial - probiotics for preterm babies	2008-12	PB(a)	
Economic evaluation alongside PROGRAMS trial - the cost effectiveness of GM-CSF for sepsis prophylaxis in preterm growth restricted babies	2001-08	SP	
Neonatal unit survey of communication, facilities and support for parents of preterm babies	2007-08	MR	
1.5 Fetal and infant effects of rare disorder of pregnancy			
Development of the British Association of Paediatric Surgeons Congenital Anomaly Surveillance System (BAPS- CASS)	2006-10	MK	
BAPS-CASS Gastroschisis surgical outcomes	2006-08	MK	
1.6 Infant Mortality			
Inequalities in infant mortality work programme	2007-09	RG	
Stream 2: Care of the healthy woman and baby	Duration	NPEU contact	
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 work in this area	of completed st	udies for	
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

WOLK III CHIS died		
2.5 Care in labour and delivery		
ELSA trial - trial of home versus hospital support in early labour	2004-08	PB(a)
EUPHRATES trial - trial of blood collector bag in third stage of labour	2001-08	PB(a)
CAESAR trial - factorial trial of caesarean section surgical techniques	2001-08	РВ
The CORONIS Trial: International study of caesarean section surgical techniques: a randomised fractional factorial trial.	2006-11	РВ
Women's experience of caesarean section: a qualitative study	2007-08	MR
Labour and delivery interventions in women from ethnic minorities	2005-08	MR
Changes in maternity care over time	2007-08	MR
An international comparison of maternity care	2007-08	MR
Women's worries about labour and birth: social and ethnic differences	2007-08	MR
Women's perceptions of maternity care	2007-08	MR
2.6 Postnatal health and care		
The protective effects of breastfeeding in a national UK survey	2005-08	MQ
Feeding twins, triplets and higher order multiples: a systematic review, secondary data analysis and development of evidence based guidelines	2007-09	MQ
Cochrane review: Formula milk versus expressed maternal breast milk for feeding preterm or low birthweight infants	2006-08	MQ
The impact of family income on child cognitive and behavioural outcomes in the UK	2007-08	MV
2.7 Organisation of maternity care		
Birthplace in England Research Programme (incorporating the Evaluation of Maternity Units in England (EMU) research programme)	2006-09	РВ

Stream 2: Care of the healthy woman and baby	Duration	NPEU contact
Birth at Home Study	2006-09	РВ
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
Stream 3: Maternal morbidity	Duration	NPEU contact
3.1 Maternal mental illness		
Systematic review of the use of the EPDS in screening for postnatal depression	2005-08	RG
Study in twins of antenatal depression	2005-08	RG
3.2 Obesity and outcome of pregnancy		
UKOSS: Surveillance of extreme obesity in pregnancy	2007-08	MK
3.3 Smoking, alcohol and drug misuse in pregnancy		
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	2007-08	MQ(a)
Impact of maternal alcohol consumption on fetal growth and preterm birth	2007-08	JK(a)
3.4 Surveillance of rare disorders of pregnancy		
Continued development of the UK Obstetric Surveillance System (UKOSS)	2005-10	MK
Surveillance of amniotic fluid embolism	2005-12	MK
Surveillance of pulmonary vascular disease	2006-11	MK
Surveillance of antenatal myocardial infarction	2006-11	MK
Surveillance of fetomaternal alloimmune thrombocytopenia	2006-08	MK
Surveillance of gastroschisis	2006-08	MK
Surveillance of different methods of treating obstetric haemorrhage	2007-08	MK
Surveillance of pregnancy in women with a renal transplant	2007-09	MK

Stream 3: Maternal morbidity	Duration	NPEU contact
Surveillance of pregnancy in women following other solid organ transplant	2007-12	MK
Surveillance of antenatal stroke	2007-09	MK(a)
Surveillance of failed intubation	2008-10	MK(a)
3.5 Complications of pregnancy		
Antenatal detection of shoulder dystocia	2007-08	MQ(a)
Stream 4: Methodology	Duration	NPEU contact
4.1 Methodological developments		
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
INLET trial - cluster trial of newsletters and educational supplements to centres participating in the INIS trial	2006-08	РВ
Dealing with childhood deaths in randomised trials (BRACELET)	2006-09	PB(a)
Programme of methodological research on economic aspects of perinatal and paediatric health care	2006-11	SP
Using verbal autopsy to assign stillbirths and neonatal causes of death	2006-08	MQ(a)
Health, medicines and self care choices made by children, young people and their families: information to support decision making	2006-09	PB(a)
Validation of a perceptions of care adjective check list for labour and birth	2007-08	MR
Evidence into practice: evaluating a child centred intervention for diabetes medicine management	2008-11	PB(a)
Preference based Health Utilities Index score for childhood conditions	2007-08	SP

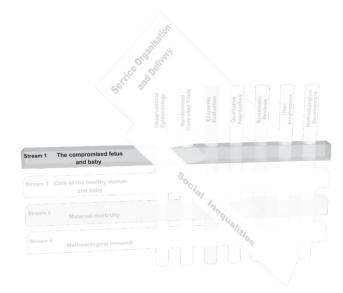
Table of Work – Studies Completed in 2006-07

Stream 1: The compromised fetus and baby	Duration	NPEU contact
Economic evaluation of outpatient cervical ripening prior to induction of labour	2005-07	SP
4Child - analysis of 15 year trends and causes of vision loss in children	2005-07	JK
Analysis of IVF success rates based on HFEA data	2006	JK
Obstetric outcomes of cancer survivors: an epidemiological study (PISCES)	2006-07	JK(a)
Association between infertility treatment and perinatal outcomes and infant health and development in a national UK survey	2004-06	MQ
Review of the perinatal outcomes of ART	2006-07	JK
Women's experience of treatment for infertility	2005-06	MR
Spina bifida follow-up - feasibility study of conducting face to face interviews with families to determine long term outcome	2005-06	JK
Spina bifida outcomes and the relationship with prenatal ultrasound findings	2005-06	JK
Myotonic dystrophy audit	2006	TB(a)
Outcome of absent stomach bubble, tracheo-oesophageal fistula (TOF), and oesophageal atresia (OA)	2006	TB(a)
Prenatal screening in Europe	2005-06	ТВ
Effect of social deprivation and fetal gender on gestational age and size at birth	2005-07	RG(a)
Economic impact of preterm birth	2005-07	SP
Neonatal networks, admissions and transfers	2005-07	MR
Nurse staffing in relation to risk adjusted mortality in neonatal care	2005-06	MR
Review of methods for neurodevelopmental follow-up of preterm infants after two years of age	2005-06	MR
Economic impact of preterm birth (II)	2006-07	SP
Stream 2: Care of the healthy woman and baby	Duration	NPEU contact
National survey of women's views and experience of maternity care - 'Recorded Delivery'	2006-07	MR

Stream 2: Care of the healthy woman and baby	Duration	NPEU contact
Feasibility study for a large national survey of women's views of maternity care	2006-07	MR
Women's experience of antenatal screening and social inequalities in access to screening	2003-07	PB(a)
Antenatal screening for Group B Strep - protocol development	2005-07	РВ
Cost effectiveness of alternative prevention and treatment strategies for GBS	2005-07	SP
ALPS trial - massage in late pregnancy and labour - pilot study	2004-06	PB(a)
Caesarean section and risk of stillbirth in subsequent pregnancy	2005-06	RG
Infant feeding and neonatal/postnatal mortality	2005-07	MQ
Systematic review of the effect of donor breast milk in preterm infants	2004-07	MQ
Socioeconomic inequalities in maternal health (MCS data analysis)	2005-07	SP
Cochrane review: Formula milk versus donor breast milk for feeding preterm or low birthweight infants	2006-07	MQ
Relationship between family income and child asthma: an econometric perspective	2006-07	SP
A model for predicting behavioural sleep problems in a random sample of Australian pre-schoolers	2006-07	JK(a)
Stream 3: Maternal morbidity	Duration	NPEU contact
Do children's sleep problems predispose mothers to depression?	2006-07	JK(a)
Review of fetal alcohol effects	2005-06	RG
Surveillance of tuberculosis in pregnancy	2005-06	MK
Surveillance of acute fatty liver of pregnancy	2005-06	MK
Surveillance and case control study of peripartum hysterectomy	2005-06	MK
Surveillance and case control study of antenatal pulmonary embolism	2005-06	MK
Surveillance and case control study of eclampsia	2005-06	MK

Stream 4: Methodological research	Duration	NPEU contact
Using record linkage to enhance and validate data collected in the Millennium Cohort Study	2004-06	MQ
Study of women's preferences for alternative management methods for first trimester miscarriage (MIST)	2006-07	SP
Social capital and its relationship with preference based measures of health status	2006-07	SP
Valuation of prenatal life in economic evaluations of perinatal interventions	2006-07	SP

Projects started in 2007



Stream 1: The compromised fetus and baby

1.1 Neonatal encephalopathy, cerebral palsy and other childhood impairments

Experience of parents of children with cerebral palsy

Chief investigator:

Eleanor Thomas, John Radcliffe Hospital

Other investigators:

Sara Ryan, University of Oxford, Clare Robertson, John Radcliffe Hospital, Jenny Kurinczuk

The aim of this qualitative study is to explore and describe the experiences of parents whose children have cerebral palsy. One particular theme which will be explored is the effects multiple appointments with different professionals have on the ability of mothers to undertake, if they desire, paid employment outside the home. Many children with cerebral palsy have multiple problems and require input from many different professionals within health, education and social services. Within health, doctors from several different specialities are likely to be involved in ongoing care, as well as therapists from other disciplines. Attendance at these appointments is time

consuming and possibly inconvenient, as families rarely get the opportunity to choose an appointment time and location that is convenient to them. The impact this has on family life and work together with other aspects of caring for a child with cerebral palsy is being explored through a series of semi-structured interviews with parents.

Contact person:

Funding:

Jenny Kurinczuk Oxfordshire Health

Services Research Committee small grant

Status of project: Ongoing

1.4 Preterm birth

Neonatal unit survey of communication, facilities and support for parents of preterm babies

Chief investigators:

Maggie Redshaw, Karen Hamilton

One of the aims of this study, which is the second element of a larger scale project (POPPY), is to establish what interventions neonatal units use to support parents of preterm babies, particularly in relation to communication, support and information. It builds on previous work by the investigators on the organisation of neonatal care. A questionnaire was developed and sent to all neonatal units in the UK. The data the survey has collected will establish a useful baseline of current facilities, practice and interventions.

Contact person: Maggie Redshaw **Funding:** NCT and Big Lottery

Status of project: Ongoing

1.6 Infant mortality

Inequalities in infant mortality work programme

Chief investigator:

Ron Gray

Other investigators:

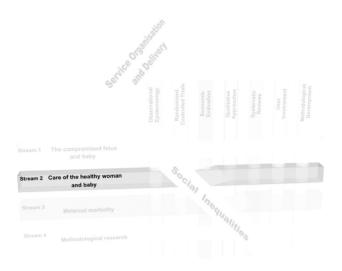
Jenny Kurinczuk, Peter Brocklehurst, Jennifer Hollowell, Olayinka Chuku The NPEU is currently undertaking a programme of work for the Department of Health to help strengthen the evidence base for interventions which reduce infant mortality and narrow the health inequalities gap. The programme will produce a series of briefings and reports with a view to helping achieve the infant mortality public service agreement (PSA) target by 2010.

The key research questions are: What are the key health service and public health interventions which address infant mortality or its three major causes, preterm birth, congenital anomalies and sudden unexpected/unexplained death in infancy, in developed countries? Which interventions have been shown to have an effect on infant mortality rates or on the rates of its three major causes by reducing risk factor prevalence? Do these interventions have a differential impact according to socioeconomic status, ethnic background or being a member of a socially excluded or disadvantaged group? What is known about barriers to implementation of interventions which have been shown to have an effect on infant mortality rates or on the rates of its three major causes? How can these barriers be overcome? Is there evidence of differential access, delivery or uptake of these interventions and if so how can these be overcome? Is there evidence on cost effectiveness of these interventions? What are the important methodological issues in measuring socioeconomic position, for example, what is the potential effect of excluding sole registrations of births on the deprivation gap? Can we identify which deaths may be preventable? The answers to these questions will inform the final set of questions: What are the implications for meeting the government public service agreement infant mortality target? What are the gaps in the evidence base and how might these be addressed?

An iterative process involving NPEU researchers and an advisory group including stakeholders at the Department of Health is being used to guide the work towards answering the research questions in a policy relevant way which will result in a number of systematic reviews and a series of expert policy briefings over a 24 month period.

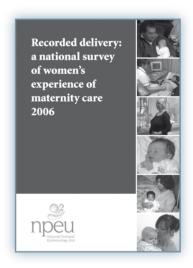
Contact person: Ron Gray

Funding: DH
Status of project: Ongoing



Stream 2: Care of the healthy woman and baby

2.5 Care in labour and delivery



Women's experience of caesarean section: a qualitative study

Chief investigator:

Maggie Redshaw

Other investigator:

Chris Hockley

This study focuses on women's experience of caesarean section as described in their own words by utilising the open ended responses to several relevant questions

from women participating in the National Maternity Survey. Questionnaires were sent out at three months post partum, with more than two-thirds of the main sample respondents providing an open text response. These data are being analysed quantitatively and qualitatively and will provide an individual perspective of the experience of women having this type of birth.

Contact person: Maggie Redshaw

Funding: DH Status of project: Ongoing

Changes in maternity care over time

Chief investigator:

Maggie Redshaw

Other investigators:

Rachel Rowe, Peter Brocklehurst, Christine Hockley, David Puddicombe

Utilising the data from the completed National Maternity Survey of women's experience of maternity care from 2,960 women, this analysis will make comparisons with the data collected in 1995 on behalf of the Audit Commission. Working with the Office for National Statistics, using the same sampling methods in 2006 as in 1995 and by using many of the same questions it is possible to examine the ways in which care and women's views about care have changed over time.

Contact person: Maggie Redshaw

Funding: DH **Status of project:** Ongoing

An international comparison of maternity care

Chief investigator:

Maggie Redshaw

Other investigators:

Gene Declercq, Boston University, Christine Hockley, Rachel Rowe

Analyses are being conducted using the data from the recent UK National Maternity Survey carried out by the NPEU. In an international collaboration comparisons will be made with data collected in a national study 'Listening to Mothers 2' carried out in the United States.

Contact person: Maggie Redshaw

Funding: DH
Status of project: Ongoing

Women's worries about labour and birth: social and ethnic differences

Chief investigator:

Maggie Redshaw

Other investigators:

Rachel Rowe, Christine Hockley, Peter Brocklehurst, Colin Martin, University of the West of Scotland

Women's worries and concerns about labour and birth and the relationship between these and socio-demographic factors are being explored using data from the National Maternity Survey, on the 2,960 respondents. The areas of concern can be categorised as focusing on uncertainty, pain and medical intervention. The characteristics which will be examined include parity, partner status, maternal educational level, ethnicity and living in an area of high or low deprivation. Factor analysis will be used to explore the possibility of developing a short scale for measuring this aspect of women's experience of pregnancy.

Contact person: Maggie Redshaw

Funding: DH
Status of project: Ongoing

Women's perceptions of maternity care

Chief investigator:

Maggie Redshaw

Other investigators:

Rachel Rowe, Christine Hockley, Colin Martin, University of the West of Scotland

As part of the National Maternity Survey women's views of their maternity care were assessed using different question formats, both structured and open ended. The questions focused on respect and kindness, being talked to in a way they could understand and the care experienced from different staff groups. Analyses are being undertaken to compare the way in which responses to the different questions map on to each other and to clinical aspects of care.

Contact person: Maggie Redshaw

Funding: DH Status of project: Ongoing

2.6 Postnatal health and care

Feeding twins, triplets and higher order multiples: a systematic review, secondary data analysis and development of evidence based quidelines

Chief investigators:

Jane Denton, Multiple Births Foundation, Maria Quigley

Other investigator:

Chris Hockley

The National Service Framework for Children, Young People and Maternity Services recommends support for breastfeeding "with particular support for mothers who have had a multiple birth". Breastfeeding rates are lower in mothers who have had a multiple birth, although the health benefits of breastfeeding may be greater because multiples are more likely to be preterm or have other health problems. Breastfeeding multiples can be challenging and there is limited information available for those involved. We are reviewing the literature on feeding of multiples, focusing on the health benefits, women's experiences and successful interventions or policies. We will describe infants' feeding practices in multiples in three large, nationally representative UK surveys. This information will be used to formulate national guidelines on feeding multiples.

Contact person: Maria Quigley **Funding:** Big Lottery **Status of project:** Ongoing

The impact of family income on child cognitive and behavioural outcomes in the UK

Chief investigator:

Mara Violato

Other investigators:

Stavros Petrou, Ron Gray, Maggie Redshaw

The association between family income and children's developmental and behavioural outcomes has been

extensively investigated by developmental psychologists. More recently the debate concerning the adverse impacts of poverty on children's development has attracted the interest of economists and policy makers. If family economic resources have a significant positive impact on children's cognitive and behavioural development, then cash transfers to low income families with children might play a crucial role in improving children's health, education and future labour market prospects. We are using data from the Millennium Cohort Study focusing on two measures of child cognitive development and one measure of child behavioural outcome assessed at age three. Our models, one for each childhood outcome, are adjusted for relevant confounders such as socioeconomic factors, parents' general and mental health, parenting practices and parents' monetary and non-monetary investments in their children's development. Filling the gap in previous research, our models also incorporate detailed information on the fathers' role.

Contact person: Mara Violato **Funding:** Medical Research

Council

Status of project: Ongoing

2.7 Organisation of maternity care



Modelling efficiency and cost effectiveness in maternity care in the UK

Chief investigator:

Liz Schroeder

Other investigators:

Stavros Petrou, Peter Brocklehurst, Maggie Redshaw

Decision analytic modelling is being used in order to determine the cost effectiveness of alternative types of maternity care. A systematic review of

the clinical effectiveness, epidemiological and economic literature related to maternity care is being conducted. The quality of the evidence will also be assessed and evidence from high quality studies will be used to estimate the baseline decision analytic model. The model will be populated by cost and outcomes data collected within a national mapping survey of maternity trusts and a programme of prospective data collection on 30 000 births that will be undertaken as part of the Birthplace project. The cost effectiveness of alternative forms of maternity care will initially be expressed in terms of an incremental cost per healthy woman and baby at hospital discharge; the composite outcome measure for the short term cost effectiveness analysis will be informed by the definition adopted by the NICE Postnatal Care Guidelines Group for a successful maternity. Given the potential sequelae of alternative forms of care, long term outcomes and costs beyond the postnatal period will be extrapolated and expressed in terms of an incremental cost per quality adjusted life year (QALY) gained. A long term model will require the mapping of disease specific outcomes onto multi-attribute utility measures, such as the EQ-5D or SF-6D. Estimates of long term hospital service utilisation and costs that can be attributed to adverse health outcomes will be drawn, in part, from the Oxford Record Linkage Study.

Contact person: Liz Schroeder

Funding: MRC Studentship, SDO

and DH

Status of project: Ongoing

Transfer from midwifery unit to obstetric unit during labour: rates, process, outcomes and women's experience

Chief investigator:

Rachel Rowe

Other investigators:

Ray Fitzpatrick, Louise Locock, University of Oxford, Jenny Kurinczuk

The overarching aim of this study is to provide information to improve the care and experience of women planning to give birth in a midwifery unit (MU), by exploring the factors associated with intrapartum transfer to obstetric units (OUs). Using data collected as part

of the Birthplace in England Research Programme, the rate of transfer during labour from both alongside and freestanding MUs throughout England for women initially at low risk of complications will be estimated. The process of transfer, including reasons for transfer, time taken and distance travelled will be described along with outcomes of mothers and babies transferred. Associations between socio-demographic and clinical factors, the process of transfer and outcomes for women will be explored. Local guidelines and protocols for the transfer of women in labour will be collected from all MUs in England, summarised and assessed against relevant national standards. The personal experiences, information and support needs of women transferred in labour will be explored and described by means of qualitative interviews with women.

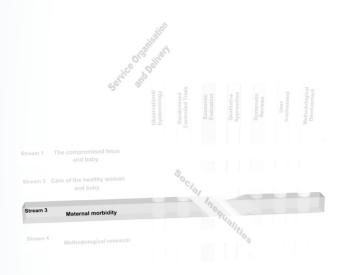
Contact person: Rachel Rowe
Funding: NIHR NCCRCD, SDO

and DH

Status of project: Ongoing



Birthplace team



Stream 3: Maternal Morbidity

3.2 Obesity and outcome of pregnancy



UKOSS: Surveillance of extreme obesity in pregnancy

Chief investigator:

Marian Knight

Other investigators:

Jenny Kurinczuk, Peter Brocklehurst

Other NPEU staff involved:

Carole Harris, Patsy Spark

Obesity is now recognised to be an important public health problem throughout the developed world. Obesity prevalence is rising rapidly in the UK in all age groups, including women of reproductive age. The proportion of women aged 25-34 with severe obesity (equivalent to a weight of about 110kg in a woman of average height) has increased from 1.3% in 1994 to 2.2% in 2004. Retrospective database analyses in Canada, Australia and the UK have identified a number of risks associated with pregnancy among obese women. Women are at risk of a number of complications of pregnancy, including pre-eclampsia (high blood pressure and

protein in the urine), blood clots and diabetes, and have higher rates of labour induction, delivery by caesarean section, general anaesthesia and anaesthetic complications. Obese women are also at increased risk of poor pregnancy outcomes, including stillbirth and neonatal death. Recent reports of the UK Confidential Enquiry into Maternal Deaths have also highlighted obesity as a factor in increasing numbers of maternal deaths in the UK. The majority of current studies focus on women with moderate obesity. The studies therefore include only a very few women who are extremely obese and have not specifically addressed the risks in this group. The risk of pregnancy complications in extremely obese women (BMI >50 or weight >140kg) is potentially even higher than among moderately obese women. This cohort study, using the UK Obstetric Surveillance System (UKOSS), will describe the risks and outcomes of pregnancy in this extremely obese group and compare them to those of a normal comparison cohort. This information will be important for future counselling, management and service provision for this group.

Contact person: Marian Knight

Funding: DH and NIHR NCCRCD

Status of project: Ongoing

3.3 Smoking, alcohol and drug misuse in pregnancy

The association between alcohol consumption in pregnancy and emotional and behavioural problems in children

Chief investigator:

Yvonne Kelly, University College London

Other investigators:

Amanda Sacker, John Kelly, University College London, Dieter Wolke, University of Warwick, Maria Quigley, Ron Gray

The link between heavy drinking during pregnancy and the risk of fetal alcohol syndrome is well established. However, it is unclear whether low levels of drinking during pregnancy may convey harm for child health and development. A recent systematic review carried out by the NPEU highlighted the need for studies

focusing on the effects of light drinking, and for investigators to use prospective population based data. Clinically relevant aspects of child behaviour that have previously been linked to mothers' drinking during pregnancy include externalising behaviours such as conduct problems and hyperactivity, and imaging studies have reported associated structural changes in the brain. Behavioural problems in childhood have been shown to predict health and well-being into adulthood. We are using data from the Millennium Cohort Study to investigate the association between alcohol consumption in pregnancy and behavioural problems at age 3 years, whilst taking account of mother and infant, socioeconomic and family psychosocial factors.

Contact person: Maria Quigley or

Yvonne Kelly

(y.kelly@ucl.ac.uk) University College

London

Status of project: Ongoing

Impact of maternal alcohol consumption on fetal growth and preterm birth

Chief investigator:

Funding:

Collen O'Leary, Telethon Institute for Child Health Research, Western Australia

Other investigators:

Natasha Nassar, Carol Bower, Telethon Institute for Child Health Research, Western Australia, Jenny Kurinczuk

The aim of this project is to investigate the relationship between prenatal alcohol exposure and fetal growth and preterm birth and, to estimate the effect of dose and timing of alcohol exposure in pregnancy. Data from a population based cohort study of 4,719 singleton births in 1995 to 1997 (the RASCALS study) are being used. The data were collected at twelve weeks postpartum using a postal questionnaire and included detailed retrospective recalled data about alcohol consumption during the three months prior to and in each trimester of pregnancy. The impact of alcohol consumption in pregnancy on fetal growth, as defined using the proportion of optimal birth weight and preterm birth (<37 weeks' gestation) is being assessed. Analyses are

being adjusted for the effects of pregnancy related and lifestyle factors including cigarette smoking.

Contact person: Jenny Kurinczuk Healthway and

Australian NHMRC

Status of project: Ongoing

3.4 Surveillance of rare disorders of pregnancy



Surveillance of different methods of treating obstetric haemorrhage

Chief investigator:

Marian Knight

Other investigators:

Jenny Kurinczuk, Peter Brocklehurst, Zarko Alfirevic, University of Liverpool, Griselda Cooper, Birmingham Women's Hospital

Other NPEU staff involved:

Carole Harris, Patsy Spark

Haemorrhage is the second most common cause of direct maternal death in the UK as identified in the most recent report of the Confidential Enquiry into Maternal Deaths. Seventeen deaths in the last triennium were reported to be directly due to haemorrhage, with a striking increase in the number of deaths from postpartum haemorrhage compared with the previous three years. The report noted the lack of denominator data to enable outcomes to be assessed with respect to particular management strategies. The basic treatment of major peripartum haemorrhage consists of surgery and/or medical management with transfusion and uterotonic drugs. There are now a number of reports of the use of other therapies, including activated factor VIIa, B-Lynch or brace sutures, arterial ligation and embolisation. There are no systematic data available at a population level to assess the clinical outcomes following use of these therapies. This UK wide descriptive study will collect information on the timing of use of these therapies, subsequent haemorrhage and requirement for additional management strategies such as hysterectomy. The information gained will be used to inform future guidelines for prevention and management.

Contact person: Marian Knight Wellbeing of Women

Status of project: Ongoing

Surveillance of pregnancy in women following other solid organ transplant

Chief investigator:

Marian Knight

Other investigators:

Jenny Kurinczuk, Peter Brocklehurst, Chris Rudge, UK Transplant

Other NPEU staff involved:

Carole Harris, Patsy Spark

Despite initial concerns about the advisability of pregnancy in women who have had transplants, there have now been reports of over 14,000 births to women with transplants. Three voluntary registers have collected information at various times: the US National Transplantation Pregnancy Register (1991-present), the UK Transplant Pregnancy Register (1994-2001) and the European Dialysis and Transplant Association Registry (1960-1992). Increasing numbers of pregnancies are now occurring in women who have had solid organ transplants other than kidneys, such as liver, heart and lung. However, the published information is insufficient to assess with confidence the outcomes of these pregnancies. This information is important in counselling and managing these women prior to and during pregnancy. The UK Transplant Register ceased to collect data in 2001 and there is currently no information available at a population level in the UK specifically relating to pregnancy. Drug treatments to prevent transplant rejection are continually developing, and more information is needed about the effects of these drugs on the mother and her infant. This project, using the UK Obstetric Surveillance System (UKOSS) will collect information about pregnancy and any associated illnesses amongst women who have a solid organ transplant (excluding kidney - see previous study) and investigate the role of anti-rejection drugs and other factors in the outcomes of women and their infants.

This information is important to inform future treatment and counselling of these women.

Contact person: Marian Knight

Funding: DH and NIHR NCCRCD

Status of project: Ongoing

Surveillance of pregnancy in women with a renal transplant

Chief investigator:

Marian Knight

Other investigators:

Jenny Kurinczuk, Peter Brocklehurst, Chris Rudge, UK Transplant

Other NPEU staff involved:

Carole Harris, Patsy Spark

Despite initial concerns about the advisability of pregnancy in solid organ transplant recipients, there have now been reports of over 14,000 births to women with transplanted organs. Most studies are centre based and retrospective. Recent analysis of data from the UK Transplant Pregnancy Register has identified high rates of preterm delivery (50%) and delivery by caesarean section (72%) in pregnant renal transplant recipients. Worse outcomes were associated with poorer pre-pregnancy graft function and drug treated hypertension during pregnancy. This register, however, no longer collects information. Immunosuppressive regimes are continually developing, and more information is needed about the intrauterine effects and neonatal consequences of immunosuppressive drugs. This project will assess the outcomes of pregnancy for both mother and infant with different immunosuppressive regimens. The relationships between different maternal and pregnancy characteristics and pregnancy outcomes will also be investigated. The information gained will be used to inform future counselling of women who are either pregnant or planning a pregnancy, and to develop management guidelines.

Contact person: Marian Knight

Funding: DH and NIHR NCCRCD

Status of project: Ongoing

Surveillance of antenatal stroke Chief investigators:

Susan Bewley, Guy's and St Thomas' Hospital, Cathy Scott, John Radcliffe Hospital

Other investigators:

Marian Knight, Tony Rudd, Beverley Hunt, Charles Wolfe, Guy's and St Thomas' Hospital

Other NPEU staff involved:

Carole Harris, Patsy Spark

Stroke associated with pregnancy is rare. The last seven Confidential Enquiries into Maternal Deaths report 144 deaths from stroke associated with pregnancy out of 1,460 deaths and over 11 million maternities. Thus the incidence of fatal stroke in the UK is 1 in 77,794 births, and the proportion of maternal deaths associated with or due to stroke is 9.5%. In addition to premature death, stroke associated with pregnancy causes ongoing disability in many survivors, which has a serious impact for mother and infant, and for families, caregivers, and health services. While much is known about the epidemiology of stroke in the elderly, the incidence, causes, and prognosis of stroke occurring in association with pregnancy or puerperium are poorly understood. Several population based studies suggest that there is an increase in the rate of all forms of stroke during the puerperium, but not during pregnancy itself. However, the estimates of incidence from different studies vary widely (from 2 to 40 per 100,000 pregnancies). The larger studies based on administrative datasets are subject to coding errors, and cannot collect information on individual cases, whilst the smaller studies are based on very few cases, and often recruit from single hospitals or specialist referral centres where incidences are higher, and estimates of the denominator population may be inaccurate. As the age of women childbearing increases, alongside an increase in other vascular risk factors, the incidence of stroke in pregnancy may be increasing. By prospectively collecting data on maternal stroke this study will provide valuable information into the epidemiology of stroke associated with pregnancy.

Contact person: Marian Knight **Funding:**

Status of project: Ongoing



UKOSS Steering Group

3.5 Complications of pregnancy

Antenatal detection of shoulder dvstocia

Chief investigator:

Lawrence Impey, John Radcliffe Hospital

Other investigators:

Peter Yeh, Rahul Roy Chowdhury, Sharmista Guha, John Radcliffe Hospital, Christine Hockley, Maria Quigley

Shoulder dystocia occurs at delivery when additional obstetric manoeuvres to release the shoulders are required following failure of gentle downward traction. Though rare, with an incidence of 0.2 - 2.0%, it is an obstetric emergency with the potential for severe morbidity and even mortality. The best known risk factor for shoulder dystocia is fetal macrosomia, but this is difficult to predict antenatally even with ultrasound. If reliable risk factors other than birth weight were considered, however, it might be that shoulder dystocia could be more accurately predicted. We are using a retrospective cohort study of more than 50,000 deliveries in the Oxford area from the OXMAT system to identify independent antenatal risk factors for shoulder dystocia.

Contact person: Maria Quigley or

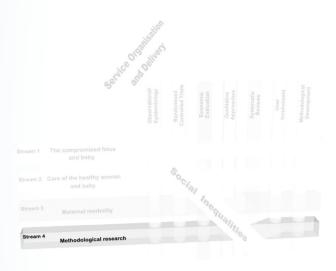
Lawrence Impey

(lawrence.impey@orh.nhs.uk) John Radcliffe Hospital

Status of project: Ongoing

Funding:

Wellbeing of Women



Stream 4: Methodological research

Validation of a perceptions of care adjective check list for labour and birth

Chief investigator:

Maggie Redshaw

Other investigator:

Colin Martin, University of the West of Scotland

This study focused on the development of an adjective checklist (PCACL-R) for use with women who have recently given birth and its psychometric characteristics, validity and reliability using factor analytic methods. Data from the National Maternity Survey undertaken by the NPEU in 2006 were used to undertake this validation.

Contact person: Maggie Redshaw

Funding: DH

Status of project: Complete -

forthcoming paper 10*

Preference based Health Utilities Index scores for childhood conditions

Chief investigator:

Stavros Petrou

Other investigator:

Emil Kupek, University of Florionapolis, Brazil

There is a paucity of published utility data for childhood health states, illnesses and conditions. This is largely explained by the methodological problems encountered when applying preference based approaches to the measurement of the health status of children. These include identifying the appropriate respondents for descriptions and valuations of childhood health status; potential sources of bias in the description and valuation processes; and the psychometric integrity of alternative measurement approaches. This study analysed data from the Sport England funded study 'Disability Survey 2000: Survey of Young People with a Disability and Sport' in order to estimate the health related quality of life and health utilities associated with a range of disabilities and clinical conditions during childhood. It is anticipated that these data will act as a future resource for cost effectiveness researchers working in the paediatric field.

Contact person: Stavros Petrou **Funding:** Medical Research

Council

Status of project: Complete - paper

submitted for publication

Publications 2006 - 2008

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- NPEU 95 Boyd PA, Rounding C, Kurinczuk JJ. First Report of the Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire (CAROBB) Births 2005-2006. Oxford: NPEU, 2008

Forthcoming Publications

- 1* Bonellie SR, Chalmers J, Gray R, Greer I, Jarvis SN, Williams C. Centile charts for birthweight and gestational age for Scottish singleton births. BMC Pregnancy and Childbirth.
- 2* Henderson J, Petrou S. A structured review of the economic implications of home births and birth centres. Birth.
- 3* Edmond KM, Quigley MA, Zandoh C, Danso S, Hurt C, Owusu Ageyi S, Kirkwood B. Aetiology of stillbirths and neonatal deaths in rural Ghana; implications for health programming in developing countries. Paediatr Perinat Epidemiol.
- 4* van den Akker O, Redshaw M. Depression in the perinatal and postnatal period continues to challenge researchers and practitioners worldwide. J Reprod Infant Psychol.
- 5* Simon J, Petrou S, Gray A. The valuation of prenatal life in economic evaluations of perinatal interventions. Health Economics.
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- 7* Hemming K, Colver A, Hutton JL, Kurinczuk JJ, Pharoah POD. The influence of gestational age on severity of disability in spastic cerebral palsy. J Pediatr.
- 8* Knight M, Nelson-Piercy C, Kurinczuk JJ, Spark P, Brocklehurst P. A prospective national study of acute fatty liver of pregnancy in the UK. Gut.
- 9* Hansen M, Petterson B, Colvin L, Kurinczuk JJ, De Klerk N, Bower C. Admission to hospital of singleton children born following assisted reproductive technologies (ART). Human Reproduction.
- 10* Redshaw M, Martin CR. Validation of a perceptions of care adjective check list. Journal of Evaluation in Clinical Practice.

NPEU Advisory Committee 2007

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Sandra Williams Deputy Director, Policy Research Programme, Chief Research

Officer - Child and Maternal Health and Sexual Health, Department

of Health

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28 September 2007)

Royal College of Obstetricians and Gynaecologists Representative

Sabaratnam Arulkumaran President, Royal College of Obstetricians and Gynaecologists (from

28 September 2007)

Royal College of Obstetricians and Gynaecologists Representative

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Practice. President elect of the Royal College of Midwives

Royal College of Midwives Representative

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Royal College of Midwives Representative (alternate)

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Sources of Funding

Summary of Income in 2007

Funder	Total (£)
Action Medical Research	61,518
BDF Newlife	12,778
Bliss – for babies born too soon, too small, too sick	54,629
British Association of Paediatric Surgeons	5,090
British Heart Foundation	61,505
Department of Health	1,324,506
Economic and Social Research Council	9,703
European Commission	8,279
Health Care Commission	62,344
Medical Research Council	1,203,434
Multiple Birth Foundation	32,465
National Childbirth Trust	18,091
Service Delivery and Organisation Programme	149,752
Tommy's the Baby Charity	20,231
Wellbeing of Women	19,089
Wellcome Trust	7,475
Miscellaneous	11,362
Grand Total	3,062,251

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