We would like to thank all the reporting anaesthetists, midwives, obstetricians and risk managers throughout the UK who have contributed to UKOSS, without whom this work would not have been possible.
This report should be cited as:
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1. Introduction

The UK Obstetric Surveillance System (UKOSS), a joint initiative between the National Perinatal Epidemiology Unit and the Royal College of Obstetricians and Gynaecologists, was launched in February 2005. The system is designed to be used to survey a range of rare conditions in pregnancy. The system is also supported by the Royal College of Midwives, the Obstetric Anaesthetists Association, the National Childbirth Trust, the Faculty of Public Health, the Confidential Enquiry into Maternal and Child Health, the Department of Health, the Health Protection Agency and the National Patient Safety Agency.

Rare conditions are difficult to study because the identification of even a small number of affected women requires collaboration between large numbers of investigators. Such collaborations are difficult to establish and may be costly, hence uncommon disorders are rarely studied comprehensively on a population basis. The information available about the natural history, prognosis, risk factors and evidence-based practice is therefore very limited. UKOSS draws together clinicians from all hospitals with consultant-led maternity units in the UK in a routine reporting system, thus allowing the straightforward conduct of a changing programme of studies of rare disorders of pregnancy. The information gained from these studies may be used to inform counselling of women, development of guidelines for prevention or treatment and for service planning. Completed studies have demonstrated the efficacy of the system for generating this information1-6.

Studies using UKOSS may be undertaken by any investigator who identifies a suitable topic7. Suitable disorders to study are those which are uncommon (usually no more than one case per 2000 births annually in the UK); are an important cause of maternal or perinatal morbidity or mortality; and which have research questions which can be suitably addressed using the UKOSS methodology (prospective descriptive, cohort or case-control studies). This report outlines the studies undertaken during the fourth year of surveillance using UKOSS.

2. Methods

Up to four nominated clinicians (anaesthetists, midwives, obstetricians and risk managers) in each hospital with a consultant-led maternity unit in the UK report to UKOSS. Every month, the nominated individuals are sent a report card with a list of conditions currently under surveillance (Figure 1). They are asked to complete a tick box indicating the number of cases which have occurred in the previous month, or if none, to return the card indicating a nil return. Only conditions with an estimated incidence of fewer than one in 2000 births are surveyed, and thus the most common response is a nil return. Nil returns are, however, extremely important as they allow us to confirm the number of women in the denominator birth cohort for each study.

On receiving a case report (return of the monthly card mailing), the UKOSS central team dispatches a data collection form to collect more detailed information about each case. The data collection forms are developed individually for each condition and are designed to be short and easily completed from a woman’s case notes without requiring reference to any other sources of information. The data collection forms seek confirmation of the appropriate case definition and additional information on risk factors, management and outcomes according to the protocol relating to each condition. UKOSS does not collect any personally identifiable information, including women’s names, addresses, dates of birth or hospital numbers. Reporting clinicians are asked to keep their own record of the names of women they have reported, in order that they can retrieve the woman’s case notes to complete the data collection form. The Patient Information Advisory Group (PIAG) and the Confidentiality and Security Advisory Group for Scotland (CSAGS) have judged that collection of information only, for the purpose of studying incidence and identifying means to improve patient care, which is not individually identifiable and does not lead to any change in management for the individual patient, is acceptable without requiring individual patient consent8,9. The UKOSS methodology and that of each individual study have been approved by the London Multi-centre Research Ethics Committee (Study ref 04/MRE02/45).

In order to perform case-control or cohort studies, information is also collected on control or comparison women for some studies. For these studies only, clinicians who report a case are asked to follow specific instructions to identify appropriate comparison women and complete a similar data collection form from their case notes. The process of selecting comparison women is individual to each study.
3. Participation

All 226 units with consultant-led maternity units in the UK contribute to UKOSS. This represents 100% participation of eligible units and effectively means that the denominator for all UKOSS studies is the entire birth cohort in the UK. The mean monthly card return rate during 2008 was 91% (Figure 2), with regional return rates varying between 86% and 95% (Figure 3). These card return rates continue the high rates obtained during the first three years of reporting, and are a testament to the dedication of reporting clinicians throughout the UK.
Figure 3: Map showing regional card return rates in 2008

- Scotland 91%
- North East 87%
- Yorkshire and the Humber 89%
- East Midlands 90%
- East of England 93%
- London 86%
- South East and Channel Islands 91%

Northern Ireland 92%
North West 88%
Wales 93%
South West 95%
4. Studies

Unless otherwise specified, the results included in this report represent analysis of cases reported and data available up to January 2009. All studies have been funded through a grant to the NPEU from the Department of Health except where indicated. Please note the data presented are provisional, not peer reviewed and definitive conclusions should not be drawn from them.

4.1 Study Timetable

Figure 4: Provisional UKOSS Study Data Collection Timetable 2008-2012

<table>
<thead>
<tr>
<th>PROJECT</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<tbody>
<tr>
<td>Amniotic Fluid Embolism</td>
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<td>Myocardial Infarction</td>
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<td>Pulmonary Vascular Disease</td>
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<td>FMAIT</td>
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<tr>
<td>Renal Transplant</td>
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<td>Non-Renal Solid Organ Transplant</td>
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<td>Extreme Obesity</td>
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<td>Therapies For Peripartum Haemorrhage</td>
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<td>Antenatal Stroke</td>
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<td>Failed Intubation</td>
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<td>Malaria</td>
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<td>Congenital Diaphragmatic Hernia</td>
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<td>Aortic dissection/aneurysm</td>
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</table>

4.2 Studies completed in 2008

4.2.1 Extreme Obesity

Key points

- Obesity is an important and growing public health problem.
- Preliminary results from this study suggest that nearly one in every thousand women delivering in the UK is extremely obese (BMI ≥ 50).
- These women have significantly more pregnancy complications and poorer outcomes than comparison women.
- Full analysis will determine whether these results are confirmed and provide additional information to guide counselling and management of this group of women.

Background

Obesity is now recognised to be an important public health problem throughout the developed world. The prevalence of obesity is rising rapidly in the UK in all age groups, including women of reproductive age. Recent reports of the UK Confidential Enquiry into Maternal Deaths have highlighted obesity as a factor in increasing numbers of maternal deaths in the UK. Retrospective database analyses in Canada, Australia and the UK have identified particular disease risks associated with pregnancy among obese women, including pre-eclampsia, venous thromboembolism and gestational diabetes, and higher rates of labour induction, delivery by caesarean section, general anaesthesia and anaesthetic complications. Obese women are also at increased risk of poor perinatal outcomes, including stillbirth and neonatal...
The majority of these studies focus on women with moderate obesity (BMI greater than 30). The studies therefore include only a very few women who are extremely obese and have not specifically addressed the risks in the extremely obese group. The risk of pregnancy complications in extremely obese women is potentially even higher than among moderately obese women. However, because of the relatively small numbers of women with this degree of obesity, a national study was needed to investigate this further. The objective of this study was to investigate the prevalence and outcomes of pregnancy in women with extreme obesity in the UK, and assess the risk of adverse outcomes attributable to obesity.

**Case definition**

**EITHER**
- Any woman weighing over 140Kg at any point during pregnancy
- Any woman with a Body Mass Index (BMI) greater than 50Kg/m\(^2\) at any point during pregnancy
- Any woman estimated to be in either of the previous categories but whose weight exceeds the capacity of hospital scales.

Reporting clinicians were also asked to collect information about one comparison woman for each case, identified as the woman delivering immediately before the case in the same hospital.

**Surveillance Period**

March 2007 – August 2008

**Interim Results**

One thousand six hundred and one (1601) cases of extreme obesity in pregnancy were reported up to January 2009 (figure 5). We have received further information about 1407 women (88%); 319 women did not meet the case definition and there were 54 duplicate reports and 16 where the notes were lost, leaving 1034 confirmed cases (351 with prevalence only information and 683 with detailed information). This represents an estimated prevalence of 9.3 extremely obese women per 10,000 maternities (95%CI 8.7-9.9 per 10,000).

**Figure 5: Cases of extreme obesity reported March 2007-August 2008**

High capacity weight equipment was not universally available for delivery of these women (figure 6).

Obese women were more likely to be older, white, multiparous and from routine and manual social groups, and were at higher risk of pregnancy and delivery complications: 11% had gestational diabetes; 10% a preterm delivery; 51% delivered by caesarean section; 2% had a severe haemorrhage; 9% of their infants were macrosomic.

No obese women died but the perinatal mortality rate among their infants was 17/1000 (95%CI 9-30).

**Conclusions**

These results suggest that nearly one in every thousand women delivering in the UK has a BMI of 50Kg/m\(^2\) or over, or weighs more than 140Kg. They have significantly more pregnancy complications and poorer pregnancy outcomes than comparison women. This has important service implications including the
need for additional high weight capacity equipment. We are currently collecting final outstanding data for this study; final analysis of the complete data will determine whether these results are confirmed and will provide additional information to guide counselling and management of this group of women.

**Figure 6: Availability of high weight capacity equipment for delivery of extremely obese women.** Figures show proportions of women for whom equipment was available

<table>
<thead>
<tr>
<th>Equipment</th>
<th>Standard</th>
<th>Special Arrangement</th>
<th>Not Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed</td>
<td>80%</td>
<td>6%</td>
<td>14%</td>
</tr>
<tr>
<td>Operating table</td>
<td>82%</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Chair</td>
<td>26%</td>
<td>33%</td>
<td>41%</td>
</tr>
<tr>
<td>Hoist</td>
<td>41%</td>
<td>21%</td>
<td>38%</td>
</tr>
</tbody>
</table>

**4.2.2 Fetomaternal Alloimmune Thrombocytopenia (FMAIT/NAIT)**

**Key points**

- FMAIT is associated with significant fetal and infant morbidity and mortality, first pregnancies are often severely affected and the diagnosis is usually made with the birth of a first affected infant.
- There is a debate about the utility of antenatal screening for the condition.
- Parallel descriptive studies using the British Paediatric Surveillance Unit and the National Blood Service database as well as UKOSS, suggest that the incidence of clinically detected FMAIT is less than one third of that estimated from prospective screening studies.

**Background**

FMAIT, also known as neonatal alloimmune thrombocytopenia or NAIT, is the most common cause of severe neonatal thrombocytopenia in otherwise well term infants, and is analogous to the fetal/neonatal anaemia caused by haemolytic disease of the newborn (HDN). The condition results from a fetomaternal incompatibility in platelet alloantigen, most commonly HPA-1a, and can lead to serious bleeding, intracranial haemorrhage and sometimes death of the fetus or infant. In contrast to HDN, first pregnancies are often severely affected and the diagnosis is usually made with the birth of a first affected infant. There is therefore a current debate about the utility of screening for the condition. A recent evaluation has identified a number of deficiencies in basic epidemiological information needed to assess the utility of antenatal screening. This study aims to address some of these deficiencies.

**Case definition**

All pregnant women with a previous child affected by fetomaternal alloimmune thrombocytopenia or pregnant women otherwise known to be alloimmunised with a platelet-incompatible fetus.

**Surveillance Period**

August 2006 – September 2008
**Interim Results**

Although data collection through UKOSS and the British Paediatric Surveillance Unit is complete, we are still completing collection of clinical data for the 34 cases identified through the National Blood Service database. These figures therefore represent interim results which may be modified when the data are complete.

There were 174 cases reported through the three reporting systems over the period October 2006 to September 2008 in an estimated 1.5 million births. Capture-recapture analysis suggests a possible additional 6 cases not notified, giving an adjusted incidence of 1.2 cases per 10,000 births (95% CI 1.0-1.4). Reporting overlap (England and part Wales only) is illustrated in figure 7.

We have received further information on 135 confirmed cases. Forty-three women (32%) were diagnosed antenatally; 33 (77%) of these women had previous affected pregnancies. Forty-five percent of women were delivered by caesarean section; 85% of antenatal cases and 29% of postnatal cases. There are 136 infants with known outcomes. For infants in whom the diagnosis was made antenatally, the median platelet count at birth was 129x10^9/L. In those diagnosed postnatally, the median platelet count at birth was 17x10^9/L. Sixty-two percent required a platelet transfusion at birth.

There were two intrauterine deaths, one infant death and nineteen infants had an intracranial haemorrhage. Twenty of these 22 cases with serious clinical problems occurred in women without a history of FMAIT.

**Figure 7: Reporting overlap for areas where information can be obtained from all three sources (England and part Wales). Note that we would only expect the 37% of cases diagnosed antenatally to be reported through UKOSS.**

**Interim Conclusions**

The incidence of clinically detected FMAIT estimated from this national study is less than one third of that estimated from prospective screening studies. More than ninety percent of cases with serious clinical problems were diagnosed postnatally, highlighting the importance of appropriate assessment of the case for antenatal screening.

**Funding**

This study is funded by Wellbeing of Women.
4.3 Studies in progress

4.3.1 Amniotic Fluid Embolism

Key points

- Amniotic fluid embolism is a leading cause of maternal mortality in the UK today.
- Estimates of incidence and mortality vary widely.
- This study incorporates the previous UK voluntary amniotic fluid embolism register.
- Preliminary analysis shows the estimated incidence using active surveillance through UKOSS is more than twice that obtained through passive registration.

Background

Amniotic fluid embolism (AFE) has been identified by the UK Confidential Enquiry into Maternal Deaths as a leading cause of maternal mortality\(^2\); the most recent report noted a three-fold increase in the number of deaths from this condition since the previous report. Estimates of incidence vary tenfold between 1.3 and 12.5 per 100,000 pregnancies\(^2\)\(^1\). Estimates of the mortality rate from this condition also vary widely\(^2\)\(^2\), from as much as 86% to more recent estimates of 16-30%. Recent retrospective database analyses suggest possible links with induction of labour and caesarean delivery\(^2\)\(^3\)\(^4\). A wide range of treatments have been described in case reports\(^2\)\(^2\), but there has been no comprehensive study of the epidemiology and management of this condition in the UK. A database of voluntary notifications was established in the UK to collect information on epidemiology and management\(^2\)\(^5\); this register was incorporated into UKOSS to improve ascertainment and allow a comprehensive study of the epidemiology and current management.

Case definition

EITHER A clinical diagnosis of AFE (acute hypotension or cardiac arrest, acute hypoxia or coagulopathy in the absence of any other potential explanation for the symptoms and signs observed)

OR A pathological diagnosis (presence of fetal squames or hair in the lungs).

Surveillance Period

February 2005 – ongoing

Interim Results

In the first four years of the study 88 cases of amniotic fluid embolism were reported. Information has been received for 83 of these cases (94%). There were 16 cases which were subsequently reported by clinicians as not cases and three duplicate reports. Nine further cases did not meet the case definition. There were thus 55 confirmed cases in an estimated 2,964,000 maternities. This gives an incidence estimate in the UK of 1.9 cases per 100,000 maternities (95% CI 1.4 to 2.4 per 100,000).

Detailed analysis of the 43 cases identified between February 2005 and January 2008 shows no evidence of change in incidence over the three years, although the study has limited power to detect any difference due to small annual case numbers. Twenty-three women (55%) had their embolism at or before delivery, the remainder after delivery. Ten women died (case fatality 23%, 95%CI 12-39%). There was one stillbirth and three neonatal deaths (all due to asphyxia before birth) amongst the 26 infants who were born to mothers who had their AFE at or before delivery, giving a perinatal mortality rate of 154 per 1000 total births (95% CI 44-349 per 1000 births). Neither mother nor infant survived in two cases. All the infants born to women who had an AFE after delivery survived.

Interim Conclusions

The estimated incidence using active surveillance is more than twice that obtained by passive registration\(^2\)\(^5\). There is no clear evidence of increasing incidence of AFE over the course of the study to date. However, the results confirm that amniotic fluid embolism should no longer be regarded as a condition with near universal maternal mortality and that high quality supportive care can result in good outcomes for both mother and baby.
4.3.2 Antenatal Stroke

**Key points**

- Stroke is an important cause of severe maternal morbidity and mortality in the UK.
- The increasing age of women at childbirth, along with other risk factors, may lead to an increase in the incidence of stroke associated with pregnancy.
- There have been no prospective national studies to estimate the incidence or outcomes of this condition.
- This study will investigate the incidence, risk factors, management and outcomes of stroke in pregnancy in the UK in order to inform future guidelines for prevention and treatment.

**Background**

The decreasing incidence of direct causes of maternal death over the past half century has led to a heightened awareness of non-obstetric factors responsible for maternal mortality. While stroke associated with pregnancy is rare (estimates of incidence from retrospective studies vary from 3 to 30 per 100,000 pregnancies), the last seven Confidential Enquiries into Maternal Deaths report 144 deaths from stroke associated with pregnancy. 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 on families, caregivers and health services. 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. The larger studies, based on administrative datasets are subject to coding errors, and can not collect information on individual cases, whilst the smaller studies are based on very few cases, and often recruit from specialist referral centres where the incidence may be 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.

**Case definition**

All women in the UK identified as having a stroke during pregnancy. To be included as a case the stroke must

**EITHER**

- Be confirmed at postmortem
- Be confirmed by a consultant neurologist or physician
- Be confirmed by diagnostic testing (e.g. MRI/CT)

**Surveillance Period**

October 2007 – October 2009

**Interim Results**

Forty-six cases were reported up to January 2009 and data returned about 33 of them (72%). 14 did not meet the case definition (the majority occurred postnatally) and there were 2 duplicates. There were thus 17 confirmed cases in an estimated 988,000 maternities. This represents an estimated incidence of 1.7 cases per 100,000 maternities (95% CI 1.0-2.8 per 100,000).

**Interim Conclusions**

These interim results suggest that the incidence of antenatal stroke in the UK is similar or lower than that estimated from the literature. Risk factor and outcome information will be assessed once data collection is complete.

**Investigators**

Cathy Scott, NHS Oxford Deanery
Susan Bewley, Anthony Rudd, Beverley Hunt, Charles Wolfe, Guys and St Thomas’ NHS Foundation Trust
Marian Knight, NPEU

**Funding**

This study is funded by Wellbeing of Women.
4.3.3 Congenital Diaphragmatic Hernia

Key points

- Currently we have limited information about the extent to which CDH is diagnosed and managed antenatally across the UK.
- Population-based incidence information and information about the impact of different management strategies is essential to provide a true picture of the prognosis for infants with CDH in the UK.
- Existing congenital anomaly registers cover only 50% of UK births and cannot be used to study the condition on a national basis.
- This study will provide a national picture of the incidence of the condition, its management and outcomes.

Background

Congenital diaphragmatic hernia (CDH) is a musculoskeletal defect of the diaphragm which occurs during fetal development. It affects between 1 in 2,000 to 1 in 4,000 births in the UK. Based on antenatal ultrasound findings the clinician can provide some, although at present incomplete, information to expectant parents about the likely immediate outcomes for their pregnancy. Available data are limited but indicate that a significant proportion of surviving infants experience substantial problems of respiratory, neurological, skeletal and gastrointestinal function and growth, and consequent disability. However, CDH is a rare condition and thus this information largely comes from case series collected over long periods of time reported from referral centres rather than population-based data which would give the full up-to-date picture.

The aim of this study is to combine the use of UKOSS, paediatric surgical and congenital anomaly reporting systems to assess the diagnosed and birth incidence of CDH in the UK and to describe the management and outcome of affected pregnancies.

Case definition

Any pregnant woman with a fetus affected by a congenital diaphragmatic hernia.

Surveillance Period

April 2009 – March 2010

Main Research Questions

- What is the current diagnosed incidence and birth incidence of CDH in the UK and in the populations not covered by a congenital anomaly register?
- What proportion of cases are diagnosed antenatally, at what gestation, how does this vary across the UK and what proportion are isolated anomalies?
- How are CDH-affected pregnancies managed, does this involve a multi-disciplinary team and does management vary by gestational age at diagnosis and the presence of chromosomal or other structural anomalies? What proportion were recruited to the on-going FETO-trial?
- What are the immediate pregnancy outcomes and do these vary across the country?
- What proportion of cases are notified through UKOSS, BAPS-CASS and congenital anomaly registers?

Interim Results and Conclusions

Data collection for this study has only just commenced and no results or conclusions are available yet.

Investigators

Marian Knight, Jennifer Kurinczuk, Peter Brocklehurst, NPEU
Mr David Howe, University of Southampton
Dr Judith Rankin, University of Newcastle
Professor Elizabeth Draper, University of Leicester
Prof Paul Losty, University of Liverpool

Funding

Action Medical Research.
4.3.4 Failed Intubation

Key points

- Although anaesthetic-related maternal deaths have decreased in number in recent years, hypoxia related to failed intubation remains a consistent cause of mortality.
- The incidence of failed intubation in the obstetric population is thought to be higher than in the non-pregnant population.
- The reasons for this higher incidence in the obstetric population are multiple.
- This study will investigate the incidence, risk factors, management and outcomes of failed intubation in the obstetric population in the UK in order to inform future guidelines for prevention and treatment.

Background

Reports from the Confidential Enquiries into Maternal Deaths have shown a decrease in the number of anaesthetic related deaths over recent years. However, a consistent cause of death is hypoxia relating to a failure to intubate and ventilate. The incidence of failed intubation among the pregnant population is estimated to be up to 8 times that of the non-pregnant population, but as yet, no national data exist.

The reasons for this higher incidence in the obstetric population are several. Anatomical changes in the airway due to physiological changes in pregnancy have been noted. Additionally, the physiological changes of a reduced functional residual capacity and an increased metabolic rate in pregnancy lead to a rapid progression to hypoxia following induction and apnoea. This adds pressure on the anaesthetist to intubate quickly before desaturation occurs. These issues are compounded by the fact that obstetric surgical procedures are now less frequently performed under general anaesthesia, so that training opportunities for junior anaesthetists are increasingly rare. The procedures are also frequently required “out of hours” when the trainee anaesthetist is likely not to be working under direct supervision. Finally, the amount of time spent in training is reduced overall.

Case definition

Any woman of over 20 weeks gestation given a general anaesthetic (whether on delivery suite or another hospital department) where a failed intubation has occurred.

Failed intubation is defined as failure to achieve tracheal intubation during a rapid sequence induction for obstetric anaesthesia, thereby initiating a failed intubation drill.

Surveillance Period

April 2008- April 2010

Interim Results

Thirty-five cases were reported up to January 2009 and data returned about 17 of them (49%). Two cases did not meet the case definition. There were thus 15 confirmed cases in an estimated 618,000 maternities.

Interim Conclusions

The study is as yet at too early a stage to draw any firm conclusions. Risk factor and outcome information will be assessed once data collection is complete.

Investigators

David Milne, Audrey Quinn, Amanda Pinder, Heather Gorton; Leeds General Infirmary.

Funding

This study is funded by the Obstetric Anaesthetists Association (OAA).
4.3.5 Malaria

Key points

- Malaria is an important cause of maternal and perinatal morbidity and mortality worldwide
- Travel-associated cases in the UK occur most commonly in the 15-44 age group
- There is no national information about the incidence of malaria in pregnancy in the UK, how these women are treated and the outcomes of pregnancy
- This study will describe the epidemiology of malaria in pregnancy in the UK and use the information to inform development and implementation of guidelines for both prevention and management

Background

Worldwide, malaria is the cause of severe maternal and perinatal morbidity and mortality. It is estimated that the population attributable fraction of maternal deaths due to malaria in sub-Saharan Africa is up to 23% and of neonatal deaths 18%32. Research in African and Asian populations shows that pregnant women are at higher risk both of acquiring disease and of suffering from more severe disease than non-pregnant women32. Malaria can cause severe anaemia, and in semi-immune populations may be associated with few other symptoms prior to the onset of severe complications such as adult respiratory distress syndrome or death, due to the sequestration of malarial parasites within the placenta33. In non-immune pregnant women, infection with falciparum malaria is more likely to lead to severe complications such as cerebral malaria than in the non-pregnant population. Infants are similarly severely affected; maternal malaria may lead to stillbirth and also preterm birth or intrauterine growth retardation, with a consequent increase in neonatal mortality.

The majority of information about malaria in pregnancy comes from populations in which malaria is endemic or epidemic. About 1500-2000 travel-associated cases of malaria are reported in the UK annually, with the peak occurring in the population aged 15-4434. However, no information exists about the number of women with malaria in the UK who are pregnant, the populations in the UK in which malaria in pregnancy occurs, how these pregnant women with malaria are treated or the consequences of the disease in these women and their infants. This information is important to develop and implement guidelines for both prevention and management. This descriptive study will describe the epidemiology of malaria in pregnancy in the UK and the outcomes for both women and their infants.

Case definition

Any women with a positive blood film for malaria parasites (or confirmed placental malaria) at any time during pregnancy or immediately postpartum (before discharge from hospital after delivery).

Surveillance Period

November 2008- October 2010

Interim Results

No cases reported to date.

Interim Conclusions

The study is at a very early stage. Identification of cases over the full study period will allow us to determine which populations the disease occurs in, how it is managed, and the outcomes for mother and infant.

Investigators

Marian Knight, Jennifer Kurinczuk, Peter Brocklehurst, National Perinatal Epidemiology Unit
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4.3.6 Multiple Repeat Caesarean Section

Key points

- Repeat caesarean section is an important cause of maternal morbidity and mortality.
- The increasing incidence of primary caesarean section in the UK may lead to an increase in the incidence of multiple repeat caesarean section.
- There have been no prospective national studies to estimate the incidence or outcomes of multiple repeat caesarean section.
- This study will investigate the incidence, management and outcomes for mother and infant of multiple repeat caesarean section. It will allow comparison between the risks associated with multiple repeat caesarean and those described in fewer repeat procedures.

Background

The incidence of primary caesarean section is rising throughout the world and the UK also demonstrates this trend\textsuperscript{35}. This is thought to be due to the introduction of fetal monitoring in labour, maternal preference, maternal obesity, and possibly defensive obstetric practice. After having three lower segment caesareans women are advised to undergo repeated elective caesarean in any subsequent pregnancies, rather than attempt a vaginal delivery\textsuperscript{36}. This practice is thought to reduce the risk of uterine rupture which can be life-threatening for both mother and baby. All caesarean procedures however, have associated risks; venous thromboembolism and haemorrhage - which are leading causes of maternal mortality, infection, and damage to the viscera. Repeated caesareans are also associated with placental invasion into the myometrium and peripartum hysterectomy. Babies born via caesarean are more likely to experience breathing difficulties and require admission to a specialist unit.

Current knowledge concerning the maternal-fetal outcomes and management of multiple repeat caesarean is limited and mainly derived from hospital-based retrospective case analysis outside of the UK\textsuperscript{37-40}. Complication rates are variously reported as not significantly different to lower order caesareans, or increased. A large cohort study of elective caesareans in North American tertiary centres described an increase in maternal morbidity with higher order procedures\textsuperscript{41}. No population-wide studies of incidence or complications have been undertaken. This study will determine the national incidence of multiple repeat caesarean section in the UK and identify the accompanying complications and their respective rates. It will allow comparison between the risks associated with multiple repeat caesarean and those described in fewer repeat procedures. It will also ascertain the current UK practice in such cases with regards to timing of elective caesarean and postnatal counselling for future pregnancies.

Case definition

Any woman giving birth to an infant via her 5th or more elective or emergency caesarean section (i.e. who has previously undergone four or more other caesarean procedures).

Surveillance Period

January 2009 – January 2010

Interim Results

Seven cases were reported in January 2009 and data has been returned for three of them (43%). One did not meet the case definition; there were thus 2 confirmed cases.

Interim Conclusions

Further surveillance will allow us to determine the number of women undergoing multiple repeat caesarean section delivery, describe how these women are managed and the outcomes for mother and infant.

Investigators

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Funding

RCOG/UKOSS Award from the Edgar Research Fellowship Fund.
4.3.7 Myocardial Infarction

Key points

- Myocardial infarction in pregnancy is known to be associated with significant maternal and fetal mortality.
- The current incidence estimate is based on a study from 1970.
- Current trends in lifestyle factors and increasing age at childbirth are likely to be leading to an increase in incidence.
- This study will provide a national picture of the incidence of the disease, its epidemiology and management.

Background

Myocardial infarction (MI) in pregnancy is known to be associated with significant maternal and fetal mortality\(^42\). The widely quoted incidence estimate of 1 in 10,000 births is based on a study conducted in 1970\(^43\). However, with current trends in lifestyle factors associated with cardiovascular disease risk and increasing age at childbirth, the incidence of MI during pregnancy can be expected to have increased. A recent retrospective database analysis from the USA\(^44\) provided evidence that this may be the case, identifying an increase in incidence of myocardial infarction in pregnancy from 1 in 73,400 pregnancies in 1991 to 1 in 24,600 in 2000. To date this is the only recent population study of this condition, although there are more than 150 individual case reports in the world literature\(^45\). A systematic review of the case reports in 1996 identified a number of features of MI during pregnancy which differed from MI outside of pregnancy, and reported a case fatality rate of 21% and a fetal mortality rate of 13%\(^42\). Normal coronary artery morphology was noted in 29% of women; MI in pregnancy may be caused by coronary artery dissection, embolus without atheroma in addition to atherosclerosis\(^42, 46\). Classic coronary risk factors appear to be the exception rather than the rule: 19% of patients had hypertension, 26% were smokers and only 2% had hyperlipidaemia. The authors of this review acknowledge the possible biases in favour of reporting of cases which are in some way unusual; a systematic prospective study on a population basis is thus clearly needed. This study will provide a national picture of the incidence of the disease, its epidemiology and management.

Case definition

All women in the UK identified as having acute myocardial infarction during pregnancy using the joint European Society of Cardiology/American College of Cardiology criteria\(^47\):

**EITHER**

- A typical rise and gradual fall (troponin) or more rapid rise and fall (CK-MB) of biochemical markers of myocardial necrosis with at least one of the following: (a) ischaemic symptoms, (b) development of pathologic Q waves on the ECG, (c) ECG changes indicative of ischaemia (ST segment elevation or depression), or (d) coronary artery intervention (e.g. coronary angioplasty)

**OR**

- Pathological findings of an acute MI.

Surveillance Period

August 2005 – ongoing

Interim Results

Forty-five cases were reported up to January 2009 and data returned about 41 of them (91%). 18 did not meet the case definition and 2 were duplicates. There were thus 21 confirmed cases, representing an estimated incidence of 8 cases per million maternities (95% CI 5-13) or 1 in 120,000 maternities.

Interim Conclusions

There have been substantially fewer cases than the expected number reported. This may be due to under-reporting, to a genuinely lower incidence or due to previous incidence estimates including postnatal cases, which are not usually identified through UKOSS. We will continue to investigate other sources of case ascertainment. We have also extended the study period from two to six years in order to allow us to generate a robust estimate of incidence at the end of the study.
4.3.8 Pregnancy in Transplant Recipients

**Key points**

- There have been over 14,000 reports of pregnancy in transplant recipients worldwide.
- The UK National Transplantation Pregnancy Register identified high rates of preterm and caesarean section delivery in renal transplant recipients, but it no longer collects information.
- Immunosuppressive regimens are continually developing.
- This study will provide a national picture of the incidence of pregnancy in solid organ transplant recipients and assess the role of immunosuppressive regimens and other factors in the outcomes of women and their infants.

**Background**

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. Three voluntary registers have collected data 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). Recent analysis of data from the UK Transplant Pregnancy Register 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 UK register, however, no longer collects information. The objective of this project is to collect information about pregnancy outcomes amongst current solid organ transplant recipients in the UK and describe the outcomes for women and their infants. The project is divided into two studies: the first to investigate outcomes in women with renal transplants and the second to investigate outcomes in women with other solid organ transplants.

**Case definitions**

Renal transplant study:

All pregnant women with a transplanted kidney, with or without other transplanted organs.

Non-renal solid organ transplant study:

All pregnant women with a transplanted solid organ, including heart, lung, liver, pancreas and small bowel. Isolated renal, corneal and bone marrow transplant recipients are excluded.

**Surveillance Period**

January 2007 - ongoing

**Interim Results**

One hundred and one cases of pregnancy in renal transplant recipients were reported, and data collection forms returned for 81 (80%). There were three duplicate cases and two which did not meet the case definition, leaving 76 confirmed cases. There have been no maternal deaths. Eight pregnancies miscarried and there was one termination of pregnancy. There were two perinatal deaths among 70 infants (including three sets of twins), giving a perinatal mortality rate of 29 per 1000 total births (95% CI 3-99 per 1000).

Thirty-four cases of pregnancy in non-renal solid organ transplant recipients were reported, and data collection forms returned for 29 (85%). There were three cases which were reported in error and no duplicates, leaving 26 confirmed cases. Twenty-two women had received liver transplants, two lung transplants, one a heart transplant and one a heart-lung transplant. The recipient of the heart transplant died; there were no other maternal deaths. Two women had a miscarriage and one infant died among 25 for whom outcomes are known.

**Interim Conclusions**

These studies are still at an early stage. The outcomes for women and their infants appear largely good, but more definitive conclusions will be drawn at the end of the studies. The study of renal transplant recipients has been extended until January 2010 to allow us to generate more robust results and the study of other solid organ transplant recipients will run until 2012.
4.3.9 Pulmonary Vascular Disease

**Key points**

- Pulmonary vascular disease in pregnancy is widely considered to pose an extreme risk of maternal death.
- There have been no recent prospective case series to assess this risk.
- Novel methods of management may impact on case outcomes.
- This study will provide a national picture of the incidence of the disease, its epidemiology and management.

**Background**

Pre-existing or gestational occurrence of pulmonary vascular disease, including Eisenmenger’s syndrome, primary and secondary pulmonary hypertension, is one of the rare conditions widely considered to pose an extreme risk of maternal death. Three of the six maternal deaths in women with congenital heart disease reported in the UK in the last triennium were associated with pulmonary vascular disease, since 1991 there have been 25 maternal deaths in the UK associated with this condition. Eisenmenger’s syndrome is estimated to carry a maternal mortality rate of 40% per pregnancy, with an infant mortality rate of 10-15%. A systematic review of the literature in 1998 suggested that the maternal mortality rate had remained unchanged over the previous 20 years. However, the authors of this review recognize that there may be inherent biases in published reports of pregnancy in women with pulmonary vascular disease in pregnancy and call for more information from detailed prospective case series in order to differentiate the risks of pregnancy and eventually provide an optimal plan of management. Cases in the UK were collected prospectively on a voluntary basis by the UK Registry of High Risk Obstetric Anaesthesia, however, problems with ascertainment caused the register to cease to collect data. The objective of this prospective study through UKOSS is to provide an appropriate national case series with good ascertainment to allow comprehensive study of the epidemiology and current management of Eisenmenger’s syndrome and pulmonary hypertension.

**Case definition**

**EITHER** Pulmonary hypertension: defined as 1) a mean (not systolic) pulmonary artery pressure equal to or greater than 25mmHg at rest or 30 mmHg on exercise in the absence of a left-to-right shunt or 2) a pulmonary artery systolic pressure greater than 36mmHg. Pulmonary hypertension may be primary (no cause identified) or secondary (known cause identified, for example, vasculitis, connective tissue disease, chronic pulmonary thromboembolism, sickle cell disease, drug use).

**OR** Eisenmenger’s syndrome: defined as pulmonary hypertension secondary to an uncorrected left-to-right shunt from a ventricular septal defect, atrial septal defect or patent ductus arteriosus.

**Surveillance Period**

March 2006 – ongoing

**Interim Results**

To date 53 cases of pulmonary vascular disease have been reported, with further information available for 45 (85%). Two duplicate cases were reported and there were 18 reported cases which did not meet the case definition (the majority being cases of pulmonary embolism), leaving 25 confirmed cases in an estimated 2.2 million maternities (incidence 12 cases per million maternities; 95% CI 8-18; 1 in 84,000 maternities). Fifteen of these cases were known prior to pregnancy and ten were diagnosed during pregnancy or immediately postnatally. Four pregnancies were terminated. One woman died (case fatality 4%; 95% CI 0.1-20%). There were no perinatal deaths among 22 infants (including one set of twins).

**Interim Conclusions**

Pulmonary vascular disease in pregnancy is extremely rare in the UK. However, the early results from this study suggest that mortality may not be as high as previously reported. This study will continue for a further three years in order to identify a larger population-based series of cases.
4.3.10 Therapies for Peripartum Haemorrhage

**Key points**

- Haemorrhage remains an important cause of maternal mortality in the UK.
- B-Lynch or brace sutures, recombinant factor VIIa and arterial embolisation or ligation are now being used more commonly to treat severe peripartum haemorrhage.
- There are no systematically collected data available at a population level to assess the clinical outcomes following use of these therapies.
- This study will describe the use of these specific therapies for treatment or prophylaxis for peripartum haemorrhage in the UK and assess the outcomes following their use.

**Background**

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. However, deaths from haemorrhage represent only the tip of the iceberg of disease; severe haemorrhage has been included in the definition of ‘near-miss’ maternal morbidity in several studies.

The basic treatment of major peripartum haemorrhage consists of surgery and/or medical management with transfusion and uterotonic drugs. However, there are now a number of reports of the use of other therapies, including recombinant factor VIIa, B-Lynch or brace sutures, ligation and embolisation of major pelvic vessels (internal iliac/uterine arteries) in cases with continued bleeding. None of these therapies have been evaluated in large randomised controlled trials, but all are used widely throughout the UK. There are no systematic data available at a population level to assess the clinical outcomes following use of these therapies. For example, there are only nine reports in the literature of failed B-Lynch sutures. However, in the UKOSS study of peripartum hysterectomy, 50 women who underwent a peripartum hysterectomy to control haemorrhage had had a B-Lynch or brace suture prior to requiring a hysterectomy. In order to assess the clinical outcomes following these therapies, we need to identify all cases in which they are used. This descriptive study will collect information on the timing of use of these therapies, subsequent haemorrhage and requirement for additional management strategies such as hysterectomy. This will allow us to investigate the outcomes associated with these specific different management strategies depending upon the timing of use in order to inform future guidelines for prevention and management.

**Case definition**

The cases will be all women in the UK treated for peripartum haemorrhage with:

- EITHER Activated factor VIIa
- OR B-Lynch or other brace suture
- OR Arterial ligation or embolisation.

**Surveillance Period**

October 2007 - March 2009

**Interim Results**

To date 433 women who had received the specific therapies for peripartum haemorrhage have been reported, with further information available for 319 (74%). Seven duplicate cases were reported and there were 82 reported cases which did not meet the case definition (the majority had a hysterectomy or other management for haemorrhage but none of the specific therapies), leaving 230 confirmed cases. 170 women were managed with brace sutures, 48 with factor VIIa and 75 with vessel embolisation or ligation; 42 women had a combination of treatments. None of these women died.

**Interim Conclusions**

The data collection for this study will be completed shortly, having been extended to March 2009 due to a smaller number of cases than expected being reported. We will then undertake confirmation of case numbers, following which detailed analysis will be undertaken.

**Funding**

This study is funded by Wellbeing of Women.
4.3.11 Uterine Rupture

Key points

- Uterine rupture is associated with significant maternal and fetal morbidity.
- A decrease in the number of women attempting vaginal birth after caesarean section may be due to concerns about the risk of uterine rupture.
- There are no systematic data available at a population level to quantify the incidence of uterine rupture and to assess the risks associated with induction and augmentation of labour in women who have had a previous caesarean delivery.
- This study will investigate the incidence, risk factors and outcomes of uterine rupture in the UK.

Background

True uterine rupture is a catastrophic event with significant associated maternal and fetal morbidity and mortality. In the developed world it most commonly occurs in women who have previously delivered by caesarean section. This observation has led to debate about the optimal management of labour and delivery in women who have delivered by caesarean section in previous pregnancies. Women with a previous caesarean delivery have generally been encouraged to attempt a trial of labour in subsequent pregnancies, but recent reports of an increased risk of morbidity, particularly due to uterine rupture, are thought to have contributed to a marked decrease in the number of women attempting vaginal birth after caesarean section. The rate of caesarean section delivery in the UK is increasing, with previous caesarean section being the most common primary obstetric indication for repeat caesarean. Two recent systematic reviews have attempted to quantify the incidence of uterine rupture. Both these reviews identified a number of deficiencies in the few existing studies in developed countries and suggested that a prospective national study of uterine rupture would offer the best opportunity to guide preventive strategies. They identified only one previous UK population-based study, which reported 12 ruptures in 48,865 deliveries, a rate of approximately 1 in 4000 deliveries.

In addition to difficulties in quantifying the incidence of uterine rupture, Guise et al. noted that existing observational studies were insufficient to answer additional questions about the risks of rupture associated with induction and augmentation of labour. The planned case-control study using UKOSS will address these questions and quantify the national incidence of uterine rupture in the UK.

Case definition

The cases will be all women identified as having a uterine rupture using the following definition: a complete separation of the wall of the pregnant uterus, with or without expulsion of the fetus, involving rupture of membranes at the site of the uterine rupture or extension into uterine muscle separate from any previous scar, and endangering the life of the mother or fetus. Any asymptomatic palpable or visualised defect (for example dehiscence noted incidentally at caesarean delivery) will be excluded.

Surveillance Period

April 2009 - April 2010

Main Research Questions

- What is the current incidence of uterine rupture in the UK?
- What are the characteristics of women who suffer from uterine rupture?
- What proportion of ruptures occur in women who have previously delivered by caesarean?
- What is the risk associated with labour induction or augmentation of labour after prior delivery by caesarean section?
- What are the outcomes for mother and infant?

Interim Results and Conclusions

Data collection for this study has only just commenced and no results or conclusions are available yet.

Investigators

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Funding

This study is funded by Wellbeing of Women.
4.4 Future studies
The following studies have been approved by the UKOSS Steering Committee and are due to commence in 2009/2010.

4.4.1 Aortic Dissection/Dissecting Aortic Aneurysm

**Key points**

- Aortic dissection in pregnancy is a significant cause of maternal morbidity and mortality.
- Changes in birth patterns, with a rise in older mothers and increased prevalence of obesity may contribute to an increased occurrence of aortic dissection in the UK.
- There have been no prospective studies to estimate the incidence of this disease and its investigation and management during pregnancy.
- This study will determine the national incidence of aortic dissection in the pregnant population in the UK and use this national initiative to characterise and quantify risk factors for aortic dissection in pregnancy.

**Background**

Aortic dissection in pregnancy is a life-threatening event to both mother and baby and accounts for 14% of maternal cardiac deaths\(^1\). Although rare, an association between pregnancy and aortic dissection has been reported and its incidence in pregnancy is rising. Approximately 50% of cases of aortic dissection in women under the age of 40 occur whilst they are pregnant\(^3\). Patients presenting with aortic dissection may do so with a wide array of symptoms and the condition may be missed or symptoms mistaken for other diseases in pregnancy\(^71\). There is often a cautious approach by clinicians to imaging studies required for diagnosis for fear of radiation effects on the baby and this may hinder prompt diagnosis\(^71\). Untimely delays in treatment of this disease can lead to potentially catastrophic consequences, since the mortality rate increases by 1% each hour if left untreated\(^73\). Current understanding of aortic dissection and its management in pregnancy is limited. Published data is mainly in the form of case reports with no clear management guidelines for this disease. Risk factors for aortic dissection within the pregnant population are equally not well-defined. Changes in birth patterns with a rise in older mothers and increased prevalence of obesity may increase the occurrence of aortic dissection, therefore an up to date understanding of the risk factors for aortic dissection in pregnancy is urgently required. This study will determine the national incidence of aortic dissection in pregnancy and will provide information on the current investigation, management and maternal-fetal outcomes of this disease in the UK.

**Case definition**

Any woman in whom the diagnosis (before or during pregnancy) of (a) aortic dissection was confirmed using suitable imaging (chest X ray, echocardiography, computed tomography, magnetic resonance imaging) or (b) aortic dissection was confirmed at surgery or postmortem.

**Surveillance Period**

September 2009 - June 2011

**Main Research Questions**

- What is the current incidence of aortic dissection in the UK?
- What are the risk factors for aortic dissection in pregnancy?
- How is aortic dissection currently diagnosed in pregnancy in the UK?
- How are the various aortic dissection subtypes in pregnancy managed in the UK?
- What are the maternal-fetal outcomes in patients diagnosed with aortic dissection

**Investigators**

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**Funding**

Heart Research UK.
5. Publications

5.1 Acute Fatty Liver of Pregnancy (AFLP)

Published article


Key points
• Nationally AFLP is rare, with an estimated incidence of 5.0 cases per 100,000 maternities (95%CI 3.8-6.5/100,000) or 1 in 20,000 maternities.
• Diagnostic criteria previously proposed agree substantially with clinical diagnosis.
• Eighteen percent of women had twin pregnancies and 20% were underweight (BMI <20). This suggests women with twin pregnancies appear to be at higher risk but further studies are needed to investigate the risk associated with low BMI.
• One woman received a liver transplant. One woman died (case fatality rate 1.8%, 95%CI 0-9.4%). There were seven deaths among 67 infants (perinatal mortality rate 104 per 1000 births, 95%CI 43-203).
• The incidence estimate from this study is lower than documented by earlier hospital-based studies, but maternal and neonatal outcomes are better than previously reported, possibly related to improved ascertainment.

5.2 Amniotic fluid embolism

Published Article

Key points
• The incidence of AFE as reported through UKOSS (1.8 cases per 100,000 maternities, 95% CI 1.3-2.4/100,000) is less than a third of that reported from a retrospective database review in the US (7.7 cases per 100,000 maternities).
• However, diagnosis of amniotic fluid embolism is difficult, and coded data may be flawed, thus limiting the accuracy of incidence estimates obtained from retrospective database review.
• We believe the observed differences are most likely to be due to the inclusion of false positive cases, i.e. those not meeting an agreed clinical definition, in the US database review, but further research is needed to determine whether any of the observed differences are not simply due to misclassification.

5.3 Ethnic Inequalities in severe maternal morbidity

Published Article
Key points

- Black Caribbean and black African women have twice as much risk of experiencing severe ‘near-miss’ maternal morbidity compared to white women. Pakistani women have a one and a half times increased risk.
- This pattern is very similar to reported ethnic differences in maternal death rates.
- For white women the estimated risk of severe complications is around 80 cases per 100,000 maternities (95% CI 73-87), 119 cases per 100,000 maternities (95% CI 83-165) for Pakistani women, 188 cases per 100,000 maternities (95% CI 110-301) for black African woman and 196 cases per 100,000 maternities (95% CI 143-261) for black Caribbean women.
- These differences may be due to the presence of pre-existing maternal medical factors, or to factors related to care during pregnancy, labour and birth, but are unlikely to be due to differences in age, socioeconomic or smoking status, body mass index or parity.
- This highlights to clinicians and policy-makers the importance of tailored maternity services and improved access to care for ethnic minority women.

5.4 TB in pregnancy

Published Article

Key points

- TB in pregnancy is rare in the UK but appears to be limited to ethnic minority women, most commonly recent immigrants.
- Extrapulmonary disease is as common as pulmonary disease and may present a diagnostic challenge.
- The prognosis for both women and infants is good.
- Primary care, obstetric and midwifery staff, particularly in areas of high TB prevalence, should be aware of the potential for nonspecific presentation of TB in pregnancy and consider the diagnosis in women, especially recently arrived immigrants, presenting with nonspecific symptoms.

5.5 Abstracts

The following abstracts have also been presented at meetings throughout the year and are available on our website www.npeu.ox.ac.uk/ukoss:

A prospective national study of acute fatty liver of pregnancy in the UK. Presented at the Obstetric Anaesthetists Association meeting May 2008.

Fetomaternal Alloimmune Thrombocytopenia (FMAIT) in the UK: A prospective national study of incidence, management and outcomes using obstetric, paediatric and laboratory reporting systems. Presented at the Perinatal Medicine meeting June 2008.

Gastroschisis in the UK: A prospective national study of prevalence, management and outcomes using obstetric, paediatric surgical and congenital anomaly reporting systems. Presented at the Perinatal Medicine meeting June 2008.
6. Acknowledgements

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References


