UKOSS rare conditions in pregnancy

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Why study maternal morbidity?

• Severe complications are uncommon
• Robust evidence to guide management and service provision is difficult to obtain
• Randomised controlled trials challenging
  – Rare conditions, large collaboration needed
  – Often require recruitment during an emergency
  – Issues of consent and capacity
“Near-miss” events

“a severe life-threatening obstetric complication necessitating urgent medical intervention in order to prevent likely death of the mother”*

- In countries where deaths are rare
  - Events associated with death may be atypical
  - Study of “near-miss” events may give more insight into risk factors and possible means of prevention

Maternal Morbidity Programmes
UK Obstetric Surveillance System (UKOSS)

- Monthly prospective case collection from obstetrician, midwife, obstetric anaesthetist and risk midwife (individualised by hospital)
- Cohort or case control studies conducted as well as descriptive studies
- Rolling programme of studies
- Central data collection
Advantages of UKOSS

• Can be used for a variety of studies
• Lessens the burden of multiple requests for information from individual clinicians
• Information used to make practical improvements in prevention, treatment and service planning
• Studies can be rapidly introduced in response to conditions of emerging public health importance
What conditions can be studied using UKOSS?

- Disorder is an important cause of perinatal or maternal morbidity or mortality
- Uncommon (<1 per 2000 births)
- UKOSS methodology is suitable
- Other data sources exist to assess or enhance ascertainment
Study Application Procedure

- Informal discussion with UKOSS team
- Outline applications discussed at management group (monthly)
- Full applications discussed by Steering Committee (four-monthly meeting)
- Investigators invited to attend Steering Committee meeting
Completed Studies

2006
• Eclampsia
• Peripartum Hysterectomy
• Acute Fatty Liver
• Antenatal PE
• TB

2007
• Gastroschisis

2008
• Extreme Obesity
• FMAIT

2009
• Therapies for Peripartum Haemorrhage
• Multiple repeat caesarean section
• Pregnancy in renal transplant recipients

2010
• H1N1v influenza in pregnancy
• Antenatal Stroke
• Failed Intubation
• Malaria
• Congenital Diaphragmatic Hernia
• Myocardial Infarction
• Uterine Rupture

2011
• Sickle cell disease in pregnancy
• Placenta accreta
• Aortic dissection
• Obstetric cholestasis

2012
• Pregnancy in non-renal transplant recipients
• Pulmonary vascular disease
• Severe maternal sepsis
• HELLP
Current Studies

- Adrenal tumours in pregnancy
- Amniotic Fluid Embolism
- Cardiac arrest in pregnancy
- Massive transfusion in obstetric haemorrhage
- Myeloproliferative disorders
- Pituitary tumours in pregnancy
- Pregnancy in women with a gastric band
- Stage 5 chronic kidney disease
Future Studies

• In planning
  – Anaphylaxis in pregnancy
  – Epidural haematoma/abscess
  – ITP in pregnancy
  – Pregnancy in women over 48
  – Pregnancy in women with artificial heart valves
Uses of UKOSS Data

• Disease incidence/prevalence
• Audit of guidelines/change in practice
• Risk factors
• Management techniques
• Public health response
• Outcomes
• Investigating disease progression
1. Incidence – Failed intubation

- 57 confirmed cases in the UK over 2 years
- 1 per 224 GAs (95% CI 179-281)‡
- Similar to estimates from smaller studies

‡Quinn A et al 2012 BJA Advance access publication
1. Incidence - Eclampsia

• 214 confirmed cases
• Incidence 2.7 per 10,000 (95% CI 2.4-3.1)‡

• Incidence in 1992 4.9 per 10,000 (95% CI 4.5-5.4)*†

* p<0.0001

‡Knight M on behalf of UKOSS 2007 BJOG 114: 1072-1078
†Douglas and Redman 1994 BMJ 309:1395-1400
## Risk Reductions

<table>
<thead>
<tr>
<th></th>
<th>Surveys 1992-2005</th>
<th>RCTs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eclampsia Incidence</strong></td>
<td>-45% (-53% to -34%)</td>
<td>-58%† (-71% to -40%)</td>
</tr>
<tr>
<td><strong>Recurrent fits</strong></td>
<td>-39% (-53% to -21%)</td>
<td>-67%‡ (-79% to -47%)</td>
</tr>
<tr>
<td><strong>Case fatality</strong></td>
<td>-100% (*)</td>
<td>-50%‡ (-76% to +5%)</td>
</tr>
<tr>
<td><strong>Severe morbidity</strong></td>
<td>-70% (-80% to -55%)</td>
<td>-13% (-29% to +6%)</td>
</tr>
<tr>
<td><strong>Perinatal deaths</strong></td>
<td>+12% (-43% to +117%)</td>
<td>-16%‡ (-34% to +7%)</td>
</tr>
</tbody>
</table>

*Not calculable
†Magpie trial Lancet 2002 359: 1877-90
‡Collaborative Eclampsia trial (Mg vs phenytoin) Lancet 1995 345: 1455-63
2. Guidelines – Antenatal PE

• 143 cases identified
• 9 women should have received LMWH according to RCOG guidelines
  – Only 3 (33%) did
• 6 women had a PE following LMWH prophylaxis
  – 3 (50%) received lower than recommended doses
  – 3 received enoxaparin 40mg once daily

Knight M on behalf of UKOSS 2008 BJOG 115: 453-461
4. Risk factors – Uterine rupture

<table>
<thead>
<tr>
<th>Category</th>
<th>Risk of Uterine Rupture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woman with previous CS in spontaneous labour</td>
<td>1 in 770</td>
</tr>
<tr>
<td>Woman with previous CS in spontaneous labour + oxytocin</td>
<td>1 in 280</td>
</tr>
<tr>
<td>Woman with previous CS induced with prostaglandin</td>
<td>1 in 360</td>
</tr>
<tr>
<td>Woman with previous CS induced + oxytocin</td>
<td>1 in 280</td>
</tr>
</tbody>
</table>

4. Management – second-line therapies for PPH

- Rate of success:
  - Uterine compression sutures, n=199: 70%
  - Surgical ligation, n=20: 32%
  - Interventional radiology, n=22: 29%
  - RFVIIa, n=31: 86%

- Need for additional therapy:
  - Uterine compression sutures, n=199: 13%
  - Surgical ligation, n=20: 5%
  - Interventional radiology, n=22: 26%
  - RFVIIa, n=31: 23%

- Hysterectomy:
  - Uterine compression sutures, n=199: 45%
  - Surgical ligation, n=20: 9%
  - Interventional radiology, n=22: 45%
  - RFVIIa, n=31: 45%

4. Management – Antivirals for H1N1

<table>
<thead>
<tr>
<th>Treated within two days</th>
<th>Admitted to ITU (n,%)</th>
<th>Not admitted to ITU (n,%)</th>
<th>Adjusted Odds Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>12 (26)</td>
<td>119 (68)</td>
<td>0.1 (0.1-0.3)</td>
</tr>
<tr>
<td>No</td>
<td>34 (74)</td>
<td>55 (32)</td>
<td>1</td>
</tr>
</tbody>
</table>

5. Public Health Response – H1N1v influenza in pregnancy

- Pregnant women hospitalised with confirmed H1N1v
6. Outcomes - obesity

<table>
<thead>
<tr>
<th></th>
<th>Obese women n (%)</th>
<th>Comparison women n (%)</th>
<th>Adjusted OR‡ (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preterm delivery</td>
<td>65 (10)</td>
<td>43 (7)</td>
<td>1.6 (1.0-2.4)</td>
</tr>
<tr>
<td>Induction</td>
<td>241 (37)</td>
<td>147 (23)</td>
<td>2.0 (1.5-2.5)</td>
</tr>
<tr>
<td>Labour</td>
<td>437 (67)</td>
<td>548 (85)</td>
<td>0.4 (0.3-0.5)</td>
</tr>
<tr>
<td>Caesarean delivery</td>
<td>328 (50)</td>
<td>140 (22)</td>
<td>3.8 (2.7-4.5)</td>
</tr>
</tbody>
</table>

‡ Adjusted for age, socioeconomic group, parity, ethnicity, smoking

## Anaesthetic outcomes

<table>
<thead>
<tr>
<th>Failure or problems with:</th>
<th>Obese women n/N (%)</th>
<th>Comparison women n/N (%)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidural</td>
<td>32/184 (17)</td>
<td>7/130 (5)</td>
<td>3.1 (1.4-7.1)</td>
</tr>
<tr>
<td>Spinal</td>
<td>28/189 (13)</td>
<td>2/112 (2)</td>
<td>9.5 (2.2-42.1)</td>
</tr>
<tr>
<td>CSE</td>
<td>6/43 (12)</td>
<td>0/12 (0)</td>
<td>*</td>
</tr>
<tr>
<td>GA for CS</td>
<td>1/37 (2)</td>
<td>0/7 (0)</td>
<td>*</td>
</tr>
</tbody>
</table>

*Unstable estimate

aOR of GA for delivery = 6.4 (2.6-15.3)
6. Outcomes – Mode of delivery in obese women

<table>
<thead>
<tr>
<th>Anaesthetic</th>
<th>Vaginal N=417 (%)</th>
<th>Caesarean N=174 (%)</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failure or problems with regional anaesthesia</td>
<td>35 (8.4)</td>
<td>18 (10.3)</td>
<td>0.72 (0.37-1.39)</td>
</tr>
<tr>
<td>General anaesthetic for delivery</td>
<td>22 (5.3)</td>
<td>15 (8.6)</td>
<td>0.55 (0.26-1.16)</td>
</tr>
<tr>
<td>Maternal postnatal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post operative wound infection or other wound complication</td>
<td>33 (26.2)</td>
<td>38 (22.4)</td>
<td>1.20 (0.68-2.13)</td>
</tr>
<tr>
<td>ICU admission</td>
<td>9 (2.2)</td>
<td>6 (3.5)</td>
<td>0.62 (0.19-2.07)</td>
</tr>
<tr>
<td>Major maternal morbidity</td>
<td>18 (4.3)</td>
<td>11 (6.3)</td>
<td>0.53 (0.23-1.24)</td>
</tr>
</tbody>
</table>

6. Outcomes – Mode of delivery in obese women

<table>
<thead>
<tr>
<th></th>
<th>Vaginal N=417 (%)</th>
<th>Caesarean N=174 (%)</th>
<th>Adjusted OR (95% CI)</th>
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</thead>
<tbody>
<tr>
<td><strong>Neonatal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Birthweight 4500g or greater</td>
<td>35 (8.4)</td>
<td>22 (12.7)</td>
<td>0.60 (0.32-1.12)</td>
</tr>
<tr>
<td>• Shoulder dystocia</td>
<td>13 (3.1)</td>
<td>0 (0)</td>
<td>NC</td>
</tr>
<tr>
<td>• Neonatal Intensive care unit admission</td>
<td>34 (8.3)</td>
<td>27 (15.5)</td>
<td>0.67 (0.34-1.30)</td>
</tr>
<tr>
<td>• Neonatal death</td>
<td>2 (0.5)</td>
<td>1 (0.6)</td>
<td>1.08 (0.09-13.2)</td>
</tr>
</tbody>
</table>

7. Investigating disease progression

Risk of severe morbidity progressing to death according to:
age ≥30; unemployment, routine or manual occupation;
black Caribbean or African ethnicity and a BMI ≥30kg/m\(^2\)

<table>
<thead>
<tr>
<th>Number of risk factors</th>
<th>OR [95%CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>1.35 (0.67-2.75)</td>
</tr>
<tr>
<td>2</td>
<td>2.77 (1.33-5.76)</td>
</tr>
<tr>
<td>3</td>
<td>4.40 (1.76-11.0)</td>
</tr>
<tr>
<td>4</td>
<td>8.45 (0.49-149)</td>
</tr>
</tbody>
</table>

The Maternal, Newborn and Infant Clinical Outcomes Review Programme
Programme of work

• Surveillance of
  – Maternal deaths
  – Perinatal deaths
  – Infant deaths up to age one year

• Confidential reviews of
  – Maternal deaths
  – Specific maternal morbidities
  – Specific perinatal/infant morbidities
Women’s and partners’ experiences – a few key messages
"True stories are...nutritious and sustaining. They feed the mind with information and the heart with hope and strength."

Philip Pullman

People's stories: see, hear and read their experiences...

Healthtalkonline is the award-winning website of the DIPEx charity and replaces the website formerly at dipex.org. Healthtalkonline lets you share in other people's experiences of health and illness. You can watch or listen to videos of the interviews, read about people's experiences and find reliable information about conditions, treatment choices and support.

The information on Healthtalkonline is based on qualitative research into patient experiences, led by experts at the University of Oxford. These
Themes

• Near-miss events can have a major impact on fathers
• Women often felt very unsupported following their transition from critical/high dependency care to the postnatal ward
• Many women and their partners express a need for ongoing counselling and experience long-term problems
• Small things can make a big difference
Summary

• The study of severe morbidity gives additional value to complement information on maternal deaths
• UKOSS studies can be used to investigate incidence, risk factors, management and outcomes of individual conditions, and audit guidelines
• Women’s and their partners’ experiences add an additional perspective
• Many of these research questions cannot be answered using any other methodology
• These studies would not be possible without the collaboration of clinicians throughout the UK
How can this help at a network level?

- Incidence – service planning
- Outcomes – network level comparisons
- Pooling network data
  - Audit
  - Guidelines
- Resources for women
- Teaching and learning
Acknowledgements

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