Amniotic Fluid Embolism (AFE) - Latest Results

This study looked at all women diagnosed with Amniotic Fluid Embolism (AFE) in the UK between February 2005 and January 2014 who were reported through UKOSS. In total 120 women were identified with 3839 in the control group.

The total incidence of AFE as estimated by the nine-years of the UKOSS study is 1.7 per 100,000 maternities and the estimated fatal incidence is 0.3 per 100,000 maternities. There was no significant temporal trend in either the total or fatal incidence. Similarly there was no notable temporal change in risk factors for AFE during the study period. Older maternal age, multiple pregnancy, placenta praevia and induction of labour were all associated with the occurrence of AFE and instrumental vaginal and caesarean deliveries were associated with the occurrence of AFE postnatally.

During the study period, twenty-three women with AFE died (case fatality 19%) and seven of the surviving women (7%) had permanent neurological injury. Women who died or had permanent neurological injury were more likely to present with cardiac arrest (83% versus 33%, p<0.001), be from ethnic minority groups (adjusted odds ratio (aOR) 2.85, 95% CI 1.02-8.00), have had a hysterectomy (unadjusted odds ratio (uOR) 2.49, 95% CI 1.02-6.06), had a shorter time interval between the AFE event and when the hysterectomy was performed (median interval 77 minutes versus 248 minutes, p=0.0315) and were less likely to receive cryoprecipitate (uOR 0.30, 95% CI 0.11-0.80).

This may reflect severity of disease at presentation, thus further investigation is needed to establish whether earlier treatments can reverse the cascade of deterioration leading to severe outcomes.

Thanks to the following hospitals who have returned cards for November 2014, December 2014 and January 2015:

- Milton Keynes Hospital NHS Foundation Trust, Milton Keynes
- Medway Maritime Hospital, Gillingham
- Macclesfield District General Hospital, Macclesfield
- Luton & Dunstable Hospital, Luton
- Calderdale Royal Hospital, Halifax
- North Devon Hospital, Barnstaple
- North Staffordshire University Hospitals, Stoke on Trent
- University Hospital of North Tees, Stockton-on-Tees
- University Hospital of Wales, Cardiff
- Victoria Hospital, Blackpool
- Victoria Hospital, Kirkcaldy
- Wansbeck General Hospital, Ashington
- Warrington and Malton Hospitals NHS FT, Warrington
- Warwick Hospital, Warwick
- West Cumberland Hospital, Whitehaven
- West Middlesex University Hospital, Isleworth
- West Suffolk Hospital, Bury St Edmunds
- West Wales General Hospital, Carmarthen
- Western Isles Hospital, Stornoway
- Wexham Park Hospital, Slough
- Whiston Hospital, Prescot
- Whittington Hospital, London
- William Harvey Hospital, Ashford
- Wishaw General Hospital, Wishaw
- Worcestershire Royal Hospital, Worcester
- Worthing Hospital, Worthing
- Wrexham Maelor Hospital, Wrexham
- Wythenshawe Hospital, Manchester
- York Hospital, York
- Ysbyty Gwynedd District General Hospital, Bangor
- Arrowe Park Hospital, Wirral
- Barnet and Chase Farm NHS Trust Maternity Unit, Barnet
- Causeway Hospital, Coerlane
- Chelsea & Westminster Hospital, London
- Colchester General Hospital, Colchester
- Derriford Hospital, Plymouth
- East Surrey Hospital, Redhill
- Furness General Hospital, Barrow-in-Furness
- Horton Maternity Hospital, Banbury
- John Radcliffe Hospital, Oxford
- Kingston Hospital, Kingston upon Thames
- Lincoln County Hospital, Lincoln
- Manor Hospital, Walsall
- Ninewells Hospital & Medical School, Dundee
- North Hampshire Hospital, Basingstoke
- North Middlesex University Hospital, Edmonton
- Pilgrim Hospital, Boston
- Pinderfields General Hospital, Wakefield
- Princess Elizabeth Hospital, St Martins
- Princess Royal Hospital, Haywards Heath
- Princess Royal University Hospital, Orpington
- Queen Charlotte's and Chelsea Hospital, London
- Rosie Maternity Hospital, Cambridge
- Royal Alexandra Hospital, Paisley
- Royal Free Hospital, London
- Royal Gwent Hospital, Newport
- Royal Hampshire County Hospital, Winchester
- Royal Jubilee Maternity Service, Belfast
- Royal Preston Hospital, Preston
- Scunthorpe General Hospital, Scunthorpe
- St James's University Hospital, Leeds
- St James's University Hospital, Liverpool
- St James's University Hospital, Leeds
- St John's Hospital, Livingston
- St Mary's Hospital, London
- St Mary's Hospital, Manchester
- St Mary's Hospital, Newport
- St Michael's Hospital, Bristol
- St Peter's Hospital, Chertsey
- St Richard's Hospital, Chichester
- Stoke Mandeville Hospital, Aylesbury
- Tameside General Hospital, Ashton-under-Lyne
- Taunton and Somerset Hospital, Taunton
- The General Hospital, Walsingham NHS Foundation Trust, Swindon
- The Jessop Wing, Sheffield
- The Tunbridge Wells Hospital, Tunbridge Wells
- Torbay Hospital, Torquay
- University College Hospital, London
- Ulster Hospital, Belfast
- University Hospital of Coventry & Warwickshire, Coventry
- University Hospital of North Durham, Durham
- University Hospital of North Staffordshire, Stoke on Trent
- University Hospital of North Tees, Stockton-on-Tees
- University Hospital of Wales, Cardiff
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- Taunton and Somerset Hospital, Taunton
- The General Hospital, Walsingham NHS Foundation Trust, Swindon
New UKOSS study – Cystic Fibrosis

**Background:** Advances in the care of people with cystic fibrosis (CF) have led to increasing survival, such that the median predicted survival age for patients in the UK with CF is now 41.4 years, and 53.1% of all females with the disease are over the age of sixteen. Fertility in menstruating females with CF is near normal, and increasingly medical professionals are confronted with issues regarding fertility, family planning and pregnancy in this patient group.

Pre-pregnancy lung function is often cited as the most important factor in predicting the outcome of pregnancy for both mother and baby. Maternal forced expiratory volume in one minute (FEV$_1$) of less than 60% correlates with increased risk of premature delivery, delivery by caesarean section and adverse fetal outcomes such as low birth weight and perinatal death. Based on the limited published evidence, a guideline was published in 2008 for the management of pregnant women with CF which states that along with pre-existing pulmonary hypertension and cor pulmonale, an FEV$_1$ of less than 50% predicted should be suggested as an absolute contraindication to pregnancy. However, successful pregnancies have been documented in women with much greater impairment in lung function and pre-pregnancy FEV$_1$, between 20% and 30% predicted are reported, leading to the suggestion that advising such women to avoid pregnancy may be unwarranted. Further study is clearly necessary to clarify the current outcomes for pregnancy in women with CF across the spectrum of lung function.

It is hoped that the results obtained from this study will guide medical professionals in supporting the care of women both planning and during pregnancy and ultimately enabling them to make informed choices regarding pregnancy and planning a family.

**Objective:** To use the UK Obstetric Surveillance System (UKOSS) to determine the incidence and risk factors of CF in pregnancy and examine the management of the condition as well as maternal and neonatal outcomes.

**Surveillance period:** March 2015 – February 2016.

**Case Definition:** All pregnant women with a diagnosis of CF confirmed by CF mutation genotyping either prior to or during the current pregnancy who are booked for antenatal care in a UK obstetric unit.

**Lead Investigator:** Lucy Mackillop, Consultant in Obstetric Medicine, John Radcliffe Hospital, Oxford.

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**Case report summary for current studies up until the end of February 2015**

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Actual number of reported cases</th>
<th>Data collection forms returned (%)</th>
<th>Number of confirmed cases (%)</th>
<th>Expected number of confirmed cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrenal Tumours (study ended 28/02/15)</td>
<td>33</td>
<td>31 (94)</td>
<td>12 (39)</td>
<td>77</td>
</tr>
<tr>
<td>Amniotic Fluid Embolism*</td>
<td>205</td>
<td>198 (97)</td>
<td>138 (70)</td>
<td>121</td>
</tr>
<tr>
<td>Anaphylaxis*</td>
<td>48</td>
<td>43 (90)</td>
<td>29 (67)</td>
<td>72</td>
</tr>
<tr>
<td>Artificial Heart Valves (study ended 30/01/15)</td>
<td>78</td>
<td>63 (81)</td>
<td>49 (78)</td>
<td>130</td>
</tr>
<tr>
<td>Aspiration in Pregnancy*</td>
<td>6</td>
<td>5 (83)</td>
<td>4 (80)</td>
<td>22</td>
</tr>
<tr>
<td>Epidural, Haematoma or Abscess</td>
<td>12</td>
<td>6 (50)</td>
<td>6 (100)</td>
<td>2</td>
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<tr>
<td>Gastric Bypass in Pregnancy</td>
<td>124</td>
<td>84 (68)</td>
<td>59 (70)</td>
<td>33</td>
</tr>
<tr>
<td>Primary ITP (study ended 30/01/15)</td>
<td>197</td>
<td>151 (77)</td>
<td>107 (71)</td>
<td>166</td>
</tr>
<tr>
<td>Vasa Praevia</td>
<td>15</td>
<td>4 (27)</td>
<td>1 (25)</td>
<td>33</td>
</tr>
</tbody>
</table>

**Funding:** * This study represents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Programme Grant RP-PG-0608-10038)
Fond farewell to a member of the UKOSS team

Patsy Spark, a Senior Programmer at the NPEU who has worked with UKOSS for many years, is due to retire this month and will be much missed by the UKOSS team. Before she goes, Melanie O’Connor, UKOSS/UKNeS Programme Manager, interviews Patsy about her time with UKOSS.

MO’C: Please could you summarise your role in UKOSS?
PS: I am the programmer for UKOSS, designing and programming all the systems to make UKOSS function as a high quality reporting system. The system has to ensure the admin team are prompted to print the cards on time, data can be efficiently entered, queries produced and sent out and a record kept of all outstanding forms and queries.

MO’C: How long have you worked with UKOSS?
PS: I have worked with UKOSS since it was a twinkle in Professor Knight's eye, about 10 years.

MO’C: Can you give a brief overview of your career to date?
PS: I started my programming career with a water company, creating programs for irrigation research. During this time I gained a degree in Maths and Computing with the Open University. I moved to medical research with Oxford University in 1998 and worked for 6 years on the Magpie Trial before moving to the NPEU. In addition to UKOSS, I have worked on the CORONIS trial for the past 7 years.

MO’C: What do you enjoy most about working with UKOSS?
PS: Unlike a clinical trial where there is only one set of data collection forms to design and program, UKOSS has collected data for 44 different conditions over the last 10 years that may affect women during their pregnancies. This means I never got bored!!

MO’C: What has been the biggest challenge you've encountered whilst working with UKOSS?
PS: Where there have been time constraints and I have had to work long hours has been the biggest challenge. Getting the database and program design correct at the beginning (including data entry forms for 5 studies!) was essential so that it could be flexible but functional and in 2009 ensuring the Pandemic Influenza study was up and running in a few weeks have been the biggest challenges.

MO’C: As mentioned above you will be retiring this month, how do you plan to spend your retirement?
PS: I am moving to Wales where I will be making a garden and keeping chickens. I will be living with my son and his children, so there is no hope of putting my feet up!

The UKOSS team would like to say a big thank you to Patsy and wish her a very happy retirement.

Chocolates this month go to Shamaura Prause from University College London for accurate form completion and Christine Edwards from Gloucestershire Royal Hospital for timely return of monthly cards and data collection forms.

Many thanks to you both!