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NEWSLETTER 41 - April 2015

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Amniotic Fluid Embolism (AFE) - Latest Results

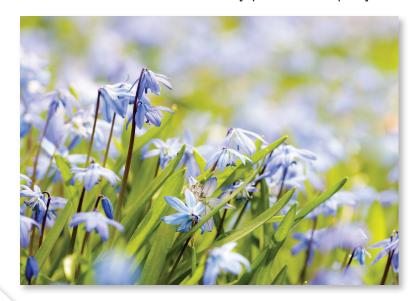
This study looked at all women diagnosed with Amniotic Fluid Embolism (AFE) in the UK between February 2005 and January 2014 who were reported through UKOSS. In total 120 women were identified with 3839 in the control group.

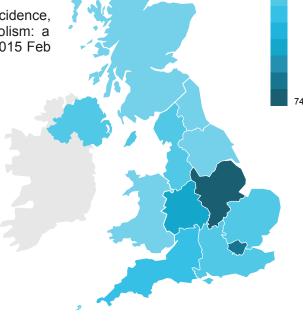
The total incidence of AFE as estimated by the nine-years of the UKOSS study is 1.7 per 100,000 maternities and the estimated fatal incidence is 0.3 per 100,000 maternities. There was no significant temporal trend in either the total or fatal incidence. Similarly there was no notable temporal change 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.

Reference: Fitzpatrick KE, Tuffnell D, Kurinczuk JJ, Knight M. Incidence, risk factors, management and outcomes of amniotic-fluid embolism: a population-based cohort and nested case-control study. BJOG. 2015 Feb 12. doi: 10.1111/1471-0528.13300. [Epub ahead of print]





UKOSS Regional Card Return Rates Map December 2014 to February 2015

THIS MONTH

New Cystic Fibrosis study starting soon

Fond farewell to a member of the UKOSS team



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

Aberdeen Maternity Hospital, Aberdeen Airedale General Hospital, Keighley Alexandra Hospital, Redditch Altnagelvin Area Hospital, Londonderry Antrim Hospital, Antrim Ayrshire Maternity Unit, Kilmarnock Barnsley Hospital NHS Foundation Trust, Barnsley

Basildon Hospital, Canvey Island Bassetlaw District General Hospital, Worksop Bedford Hospital, Bedford Birmingham City Hospital, Birmingham Birmingham Heartlands Hospital, Birmingham Birmingham Women's Hospital, Birmingham Borders General Hospital, Borders Bradford Royal Infirmary, Bradford Bronglais Hospital, Aberystwyth Broomfield Hospital, Chelmsford Caithness General Hospital, Wick

Calderdale Royal Hospital, Halifax Chesterfield & North Derbyshire Royal Hospital, Chesterfield City Hospitals Sunderland NHS Trust, Sunderland

Countess of Chester Hospital, Chester Craigavon Area Hospital, Portadown Croydon University Hospital, Thornton Heath Cumberland Infirmary, Carlisle Daisy Hill Hospital, Newry

Darent Valley Hospital, Dartford Darlington Memorial Hospital, Darlington Derby Hospitals NHS Foundation Trust, Derby Dewsbury and District Hospital, Dewsbury Diana Princess of Wales Hospital, Grimsby Doncaster Royal Infirmary, Doncaster Dorset County Hospital, Dorchester Dr Gray's Hospital, Elgin

Dumfries & Galloway Royal Infirmary, Dumfries Ealing Hospital NHS Trust, London East Sussex Healthcare NHS Trust,

St Leonards-on-Sea Epsom General Hospital, Epsom Forth Valley Royal Hospital, Larbert Frimley Park Hospital, Camberley George Eliot Hospital, Nuneaton Glan Clwyd District General Hospital,

Bodelwyddan Gloucestershire Royal Hospital, Gloucester Good Hope Hospital, Sutton Coldfield Guy's and St Thomas' Hospital, London Harrogate District Hospital, Harrogate Hereford County Hospital, Hereford

Hinchingbrooke Hospital NHS Trust, Huntingdon Homerton University Hospital, London

Hull Royal Infirmary, Hull Ipswich Hospital, Ipswich

James Cook University Hospital, Middlesbrough James Paget University Hospitals Trust,

Great Yarmouth

Jersey General Hospital, St Helier Kettering General Hospital, Kettering King's College Hospital, London King's Mill Hospital, Sutton in Ashfield Lancashire Women and Newborn Centre, Burnley Leeds General Infirmary, Leeds Leighton Hospital, Crewe Lister Hospital, Stevenage Liverpool Women's Hospital, Liverpool

Luton & Dunstable Hospital, Luton Macclesfield District General Hospital,

Macclesfield Medway Maritime Hospital, Gillingham Milton Keynes Hospital NHS Foundation Trust,

Milton Keynes Nevill Hall Hospital, Abergavenny New Cross Hospital, Wolverhampton Nobles Hospital, Douglas

Norfolk & Norwich University Hospital, Norwich North Devon District Hospital, Barnstaple North Manchester General Hospital, Manchester Northampton General Hospital, Northampton Northwick Park Hospital, Harrow Nottingham City Hospital, Nottingham Nottingham University Hospitals NHS Trust, Nottingham

Peterborough City Hospital, Peterborough Prince Charles Hospital, Methyr Tydfil Princess Alexandra Hospital, Harlow Princess Anne Hospital, Southampton Princess of Wales Hospital, Bridgend Princess Royal Maternity Hospital, Glasgow Queen Alexandra Hospital, Portsmouth Queen Elizabeth Hospital, Gateshead Queen Elizabeth Hospital, Kings Lynn Queen Elizabeth Hospital, London Queen Elizabeth the Queen Mother Hospital, Margate

Queen's Hospital, Burton upon Trent Queen's Hospital, Romford Raigmore Hospital, Inverness

Rotherham District General Hospital, Rotherham Royal Albert Edward Infirmary, Wigan

Royal Berkshire Hospital, Reading Royal Bolton Hospital, Bolton Royal Cornwall Hospital, Truro

Royal Devon & Exeter Hospital, Exeter Royal Glamorgan Hospital, Llantrisant Royal Lancaster Infirmary, Lancaster

Royal London Hospital, London Royal Oldham Hospital, Oldham

Royal Surrey County Hospital, Guildford Royal Sussex County Hospital, Brighton

Royal United Hospital, Bath

Royal Victoria Infirmary, Newcastle-upon-Tyne

Russells Hall Hospital, Dudley Salisbury District Hospital, Salisbury Scarborough Hospital, Scarborough Scunthorpe General Hospital, Scunthorpe Simpson Centre for Reproductive Health,

. Edinburgh

Singleton Hospital, Swansea South Tyneside NHS Foundation Trust, South Shields

South West Acute Hospital, Enniskillen Southend University Hospital NHS FT,

Westcliff-on-Sea Southern General Hospital, Glasgow

Southmead Hospital, Bristol Southport & Ormskirk Hospital NHS Trust, Ormskirk

St George's Hospital, London

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 Great Western Hospitals 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,

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

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, Coleraine 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

Stepping Hill Hospital, Stockport The Hillingdon Hospitals NHS Foundation Trust,

Uxbridge

The Portland Hospital, London University Hospital Lewisham, London

Watford General Hospital, Watford

Whipps Cross University Trust Hospital, London Yeovil Women's Hospital, Yeovil

Leicester Royal Infirmary, Leicester Newham General Hospital, London

Poole Hospital, Poole

Princess Royal Hospital, Telford St Helier Hospital, Carshalton Leicester General Hospital, Leicester

Returned all three cards. Returned two cards. Returned one card. No Cards Returned.



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.

Gastric Bypass Study Extension!

We are pleased to announce that the Gastric Bypass study is to be extended for another 12 months. We will therefore now be collecting data until 31st March 2016.



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

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

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)

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GMC Revalidation and NMC Continual Professional Development

We are aware that as part of your GMC revalidation or NMC Continual Professional Development, you are required to provide evidence of participation in national audit and research. If any UKOSS reporters would like to receive a certificate confirming their contribution to UKOSS, please email us at ukoss@npeu.ox.ac.uk and we will get one posted out to you.





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!



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