The national system to study rare disorders of pregnancy - UKOSS reaches 100%!

All 230 consultant-led maternity units in the UK are now participating in UKOSS – 100%!

Thank you to all of you for your fantastic ongoing efforts. Monthly response rates have now reached 90%, with two regions (North East and Northern Ireland) regularly reaching 100% monthly returns. For those of you who are curious, the map below shows the UKOSS regions, and the regional response rates for the first seven months. Congratulations again to Northern Ireland and the North East!

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Actual Number of Cases</th>
<th>Expected Number of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Fatty Liver</td>
<td>38</td>
<td>56</td>
</tr>
<tr>
<td>Amniotic Fluid Embolism</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Antenatal Pulmonary Embolism</td>
<td>75</td>
<td>35</td>
</tr>
<tr>
<td>Eclampsia</td>
<td>177</td>
<td>175</td>
</tr>
<tr>
<td>Myocardial Infarction</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Peripartum Hysterectomy</td>
<td>212</td>
<td>175</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>58</td>
<td>119</td>
</tr>
</tbody>
</table>

230 hospitals returned cards. 567 cases reported.
Thanks to the following hospitals who have returned cards for June, July or August:

- Aberdeen Maternity Hospital
- Airedale General Hospital
- Alexandra Hospital
- Altnagalvin Area Hospital
- Antrim Hospital
- Arrowe Park Hospital
- Barnet and Chase Farm Hospitals
- Barnsley District General Hospital
- Bedford Hospital
- Birmingham City Hospital
- Birmingham Heartlands Hospital
- Birmingham Women's Hospital
- Borders General Hospital
- Bradford Royal Infirmary
- Bronglais Hospital
- Burnley General Hospital
- Brunei General Hospital
- Calderdale Royal Hospital
- Causeway Hospital
- Chelsea & Westminster Hospital
- Cheltenham General Hospital
- Chesterfield & North Derbyshire Royal Hospital
- City General Hospital
- City Hospitals Sunderland NHS Trust
- Colchester General Hospital
- Conquest Hospital
- Countess of Chester Hospital
- Craigavon Area Hospital
- Cumberland Infirmary
- Dartford Hospital
- Darent Valley Hospital
- Darlington Memorial Hospital
- Derby City General Hospital
- Derriford Hospital
- Dewsbury and District Hospital
- Diana Princess of Wales Hospital
- Doncaster Royal Infirmary
- Dorset County Hospital
- Dr Gray's Hospital
- Dumfries & Galloway Royal Infirmary
- Ealing Hospital
- East Surrey Hospital
- Eastbourne District General Hospital
- Epsom General Hospital
- Erne Hospital
- Fairfield General Hospital
- Forth Park Hospital
- Friargate Hospital
- Frimley Park Hospital
- Furness General Hospital
- George Elyc Hospital
- Glyn Clwyd District General Hospital
- Gloucestershire Royal Hospital
- Good Hope Hospital
- Guy's and St Thomas' Hospital
- Harold Wood Hospital
- Harrogate District Hospital
- Heatherwood Hospital
- Hereford County Hospital
- Hexham General Hospital
- Hillingdon Hospital
- Hinchingbrooke Hospital
- Homerton Hospital
- Horton Hospital
- Hospital of St John and St Elizabeth
- Hudnott Royal Infirmary
- Hull Royal Infirmary
- Ipswich Hospital
- James Cook University Hospital
- James Paget Hospital
- Jersey General Hospital
- John Radcliffe Hospital
- Kettering General Hospital
- King George Hospital
- Kings College Hospital
- King's Mill Hospital
- Kingston Hospital
- Lagan Valley Hospital
- Leeds General Infirmary
- Leicester General Hospital
- Leicester Royal Infirmary
- Leighton Hospital
- Lincoln County Hospital
- Lister Hospital
- Liverpool Women's Hospital
- Llandough Hospital
- Luton & Dunstable Hospital
- Macclesfield District General Hospital
- Maidstone General Hospital
- Manor Hospital
- Mater Infirmorum Hospital
- Mayday University Hospital
- Medway Maritime Hospital
- Mid-Ulster Hospital
- Milton Keynes General Hospital
- Nevill Hall Hospital
- New Cross Hospital
- Newham General Hospital
- Ninewells Hospital & Medical School
- Nobles Hospital
- Norfolk & Norwich University Hospital
- North Devon District Hospital
- North Hampshire Hospital
- North Manchester General Hospital
- North Middlesex Hospital
- North Tyneside General Hospital
- Northampton General Hospital
- Northwick Park Hospital
- Nottingham City Hospital
- Pembury Hospital
- Peterborough Maternity Unit
- Pilgrim Hospital
- Pontefract General Infirmary
- Poole Hospital
- Prince Charles Hospital
- Princess Alexandra Hospital
- Princess Anne Hospital
- Princess Elizabeth Hospital
- Princess of Wales Hospital
- Princess Royal Hospital
- Princess Royal University Hospital, Orpington
- Queen Charlotte's and Chelsea Hospital
- Queen Elizabeth Hospital, Gateshead
- Queen Elizabeth Hospital, Kings Lynn
- Queen Elizabeth Hospital, London
- Queen Elizabeth II Hospital
- Queen Elizabeth the Queen Mother Hospital
- Queen Mary's Hospital
- Queen Mother's Hospital
- Queen's Hospital
- Queen's Medical Centre
- Queen's Park Hospital
- Raigmore Hospital
- Rochdale Infirmary
- Rosie Maternity Hospital
- Rotherham District General Hospital
- Royal Albert Edward Infirmary
- Royal Alexandra Hospital
- Royal Berkshire Hospital
- Royal Brompton Hospital
- Royal Cornwall Hospital
- Royal Devon & Exeter Hospital
- Royal Free Hospital
- Royal Glamorgan Hospital
- Royal Gwent Hospital
- Royal Hampshire County Hospital
- Royal Jubilee Maternity Service
- Royal Lancaster Infirmary
- Royal London Hospital
- Royal Oldham Hospital
- Royal Surrey County Hospital
- Royal United Hospital
- Royal Victoria Infirmary
- Russells Hall Hospital
- Sandwell District General Hospital
- Scarborough Hospital
- Southend General Hospital
- Solihull Hospital
- South Tyneside District Hospital
- Southend Hospital
- Southern General Hospital
- Southampton Hospital
- Southport & Ormskirk Hospital NHS Trust
- St George's Hospital
- St Helier Hospital
- St James's University Hospital
- St John's Hospital
- St John's Unit at Howden
- St Mary's Hospital, London
- St Mary's Hospital, Manchester
- St Mary's Hospital, Newport
- St Mary's Hospital, Portsmouth
- St Michael's Hospital
- St Peter's Hospital
- St Richard's Hospital
- Staffordshire General Hospital
- Stepping Hill Hospital
- Stirling Royal Infirmary
- Stoke Mandeville Hospital
- Tameside General Hospital
- Taunton and Somerset Hospital
- The Great Western Hospital
- The Jessop Wing
- The Portland Hospital
- Torbay Hospital
- Trafford General Hospital
- Ulster Hospital
- University College Hospital
- University Hospital Lewisham
- University Hospital of Hartlepool
- University Hospital of North Durham
- University Hospital of North Tees
- University Hospital of Wales
- Victoria Hospital
- Walsgrave Hospital
- Wansbeck General Hospital
- Warrington Hospital
- Warwick Hospital
- Watford General Hospital
- West Cumberland Hospital
- West Middlesex University Hospital
- West Suffolk Hospital
- West Wales General Hospital
- Western Isles Hospital
- Wrexham Park Hospital
- Whips Cross Hospital
- Whiston Hospital
- Whittington Hospital
- William Harvey Hospital
- Wishaw General Hospital
- Withybush Hospital
- Worcestershire Royal Hospital
- Worthing Hospital
- Wrexham Maelor Hospital
- Wycombe General Hospital
- Wythenshawe Hospital
- Yeovil Women's Hospital
- York Hospital
- Ysbyty Gwynedd District General Hospital
What happens when UKOSS studies finish?

When each UKOSS study starts, we have an estimate of how many cases we expect to identify over the course of a year. For some conditions, such as eclampsia and peripartum hysterectomy, we expect to identify about 300 affected women in one year. Information about this number of women will be sufficient to answer the research questions identified at the start of the studies and we will therefore stop collecting case reports after one year. Other conditions are much rarer. For example, we are only expecting to identify 10-20 women per year in the UK with amniotic fluid embolism, and we will therefore carry on collecting case reports for several years in order to obtain enough information to answer the research questions with certainty.

When the studies are finished, we will analyse the data as quickly as possible in order to feedback information which can be used to improve patient care. We hope to present the provisional results of the first studies towards the middle of next year with results finalised for publication at the end of the year. The UKOSS Steering Committee has developed strict guidelines to ensure that all data collected is submitted for publication within two years of study completion and results disseminated appropriately to ensure that any findings can be used to help clinical care as quickly as possible.

New studies will be started to take their place, but we need your ideas! UKOSS will ultimately become a system whereby studies are run entirely by external researchers. The UKOSS central team will serve only to ensure the appropriateness of studies, collect and clean data and pass the information on to the research team. So, if you have a burning question which you would like to answer through UKOSS, let us know!

Queries

Why do I keep receiving requests for missing or incomplete information? We have a number of automatic computer checks which are made when we enter the information you provide on the data collection forms into our database. If there is missing information, or values which are outside the range we would expect for particular answers, then we will send you a query. If you do not have the information to answer any particular question, please put a note on the data collection form and this should prevent any further requests for more information.

Nil Returns

Why do we ask you to fill in ‘nothing to report’ boxes?

Because these conditions are rare, missing information about one or two cases could make a big difference to our estimate of exactly how often these conditions occur. We therefore ask you to fill in a nil return so that we can be certain that there are no cases, and it is not simply that a case report has been lost in the post.

Surveillance which operates in this way is known as ‘negative’ surveillance, as we are seeking both positive and negative case reports.
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at...
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The British Maternal Fetal Medicine Society Meeting, Cardiff 6-7th April 2006
Obstetric Anaesthesia 2006, Glasgow 11-12th May 2006

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Management of the Labour Ward Course, RCOG 4th October
Baby Lifeline Obstetric Emergencies Course, Leeds 20th October

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e-mail: UKOSS@npeu.ox.ac.uk
Carole Harris: 01865 289714
web: www.npeu.ox.ac.uk/UKOSS

The Chocolate Box
Congratulations to Tony Rose from Blackburn who holds the record for the quickest return of data collection forms, and to Fran Gill from Leicester who has coordinated the most returns. We have provided Carole with a supply of chocolates of her own so she shouldn’t hold on to these for too long...

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Queen’s Park Hospital, Blackburn
St Mary’s Hospital, London
The Jessop Wing, Sheffield
Trafford General Hospital
Wexham Park Hospital, Slough

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