



Royal College of
Obstetricians
and Gynaecologists

UKOSS

UK Obstetric Surveillance System



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Happy Birthday UKOSS!

This year we are celebrating 20 years of the UK Obstetric Surveillance System.

Over the past 20 years, the UKOSS platform has been used to gather data for 90 published studies. These studies have been referenced in policy documents and clinical guidelines over 270 times by organisations in 27 countries, and have been cited in over 7000 academic journal articles.

This could never have been achieved without the hard work and support of all UKOSS reporters over the years so we would like to extend a heartfelt thank you to you all.

Here's to the next 20 years!

Epilepsy – results published

We are pleased to announce that the results for the Epilepsy in pregnancy study have now been published on NIHR Open Research.

The characteristics, clinical management and pregnancy outcomes in women with severe, uncontrolled epilepsy were compared to those of women with well controlled epilepsy. 94 cases were identified and compared with 186 controls. The study found that women with severe, uncontrolled epilepsy were significantly more likely to be admitted for seizure management in the year before pregnancy (42/94 cases vs 10/186 controls, adjusted odds ratio [aOR]=7.38 [95% CI 2.70-20.2]). They were also more likely to experience preterm birth, before 37 weeks gestation (20/94 cases vs 8/186 controls, aOR=7.61 [95% CI 2.87-20.2]).

The study concluded that women with epilepsy who are admitted to hospital to manage seizures in the year preceding pregnancy are at greater risk of severe epilepsy during pregnancy as well as preterm birth. These women should be prioritised and reviewed by a specialist as early as possible during pregnancy. All clinicians should be made aware of the importance of contraception and pregnancy planning when caring for non-pregnant women with epilepsy who are admitted to hospital with seizures.

The full paper can be found here <https://openresearch.nihr.ac.uk/articles/4-53>.

Reference: Kemp B, Kelso A, Williams D and Knight M. Severe, uncontrolled epilepsy in pregnancy: A population-based case-control study [version 1; peer review: 1 approved with reservations]. NIHR Open Res 2024, 4:53

THIS MONTH

- Steering Committee Vacancy!
- Study reminders



Hospital Monthly Reporting Rates over SIX MONTHS (June - November 2024)

6 months reported, 4 or 5 months reported, 2 or 3 months reported, 1 month reported, 0 months reported

Aberdeen Maternity Hospital	Princess Alexandra Hospital	Antrim Hospital
Altnagelvin Area Hospital	Princess Anne Hospital	Barnet Hospital (Royal Free London NHS Foundation Trust)
Aneurin Bevan University Health Board	Princess of Wales Hospital	Bradford Royal Infirmary
Arrowe Park Hospital	Princess Royal Hospital (Telford)	Darlington Memorial Hospital
Ayrshire Maternity Unit	Princess Royal Maternity Hospital	Doncaster Royal Infirmary
Barnsley Hospital	Queen Alexandra Hospital	Dumfries & Galloway Royal Infirmary
Basingdon University Hospital	Queen Charlotte's and Chelsea Hospital	East Surrey Hospital
Basingstoke and North Hampshire Hospital	Queen Elizabeth Hospital (Gateshead)	Guy's and St Thomas' Hospital
Bassetlaw District General Hospital	Queen Elizabeth Hospital (King's Lynn)	Frimley Park Hospital
Bedford Hospital	Queen Elizabeth the Queen Mother Hospital	Hereford County Hospital
Borders General Hospital	Queen's Hospital (Burton-on-Trent)	Homerton University Hospital
Bronglais Hospital	Rosie Maternity Hospital	Ipswich Hospital
Broomfield Hospital	Rotherham District General Hospital	James Cook University Hospital
Caithness General Hospital	Royal Albert Edward Infirmary	James Paget University Hospital
Calderdale Royal Hospital	Royal Alexandra Hospital	King's College Hospital
Chesterfield Royal Hospital	Royal Cornwall Hospital	Lancashire Women and Newborn Centre
City Hospital (Birmingham)	Royal Derby Hospital	Liverpool Women's Hospital
Colchester General Hospital	Royal Hampshire County Hospital	Norfolk & Norwich University Hospital
Conquest Hospital (East Sussex Healthcare NHS Trust)	Royal Lancaster Infirmary	Northwick Park Hospital
Countess of Chester Hospital	Royal Surrey County Hospital	Princess Royal University Hospital
Craigavon Area Hospital	Royal Sussex County Hospital	Queen's Hospital (Romford)
Croydon University Hospital	Royal United Hospital	Queen's Medical Centre
Cumberland Infirmary	Royal Victoria Infirmary	Raigmore Hospital
Daisy Hill Hospital	Salisbury District Hospital	Royal Jubilee Maternity Service
Darent Valley Hospital	Scunthorpe General Hospital	Scarborough Hospital
Derriford Hospital	Simpson Centre for Reproductive Health	Southend University Hospital
Diana Princess of Wales Hospital	Singleton Hospital	St Mary's Hospital (London)
Dorset County Hospital	South West Acute Hospital	St Richard's Hospital
Epsom General Hospital	Southern General Hospital	Tameside General Hospital
Forth Valley Royal Hospital	St George's Hospital	University Hospital of Wales
Furness General Hospital	St Helier Hospital	Watford General Hospital
George Eliot Hospital	St James's University Hospital	Whipps Cross University Trust Hospital
Glan Clwyd District General Hospital	St John's Hospital	North Middlesex University Hospital
Glangwili General Hospital	St Mary's Hospital (Isle of Wight)	Princess Elizabeth Hospital (Guernsey)
Gloucestershire Royal Hospital	St Mary's Hospital (Manchester)	Royal Devon & Exeter Hospital
Good Hope Hospital	St Michael's Hospital	Southmead Hospital
Harrogate District Hospital	Stepping Hill Hospital	St Peter's Hospital
Heartlands Hospital	Stoke Mandeville Hospital	University Hospital Lewisham
Hinchingbrooke Hospital	Sunderland Royal Hospital	Airedale General Hospital
Hull Royal Infirmary	The Great Western Hospital	Chelsea & Westminster Hospital
Jersey General Hospital	The Jessop Wing	Leicester General Hospital
Kettering General Hospital	The Portland Hospital	Leicester Royal Infirmary
King's Mill Hospital	The Tunbridge Wells Hospital	Luton and Dunstable University Hospital
Kingston Hospital	Torbay Hospital	Royal Berkshire Hospital
Lancashire Teaching Hospitals (Royal Preston Hospital)	Ulster Hospital	Royal Free Hospital
Leeds General Infirmary	University Hospital Coventry	Birmingham Women's Hospital
Leighton Hospital	University Hospital of North Durham	John Radcliffe Hospital
Lincoln County Hospital	University Hospital of North Midlands	Newham General Hospital
Lister Hospital	University Hospital of North Tees	Princess Royal Hospital (Haywards Heath)
Manor Hospital (Walsall)	Victoria Hospital (Blackpool)	Queen Elizabeth Hospital (Woolwich)
Medway Maritime Hospital	Victoria Hospital (Kirkcaldy)	Royal Bolton Hospital
Milton Keynes University Hospital	Warrington Hospital	Royal London Hospital
Musgrove Park Hospital	Warwick Hospital	Royal Oldham Hospital
New Cross Hospital	West Cumberland Hospital	Russells Hall Hospital
Ninewells Hospital & Medical School	West Middlesex University Hospital	The Hillingdon Hospital
Nobles Hospital (Isle of Man)	West Suffolk Hospital	University College Hospital
Northampton General Hospital	Western Isles Hospital	
North Devon District Hospital	Wexham Park Hospital	
North Manchester General Hospital	Whiston Hospital	
Northumbria Specialist Emergency Care Hospital	Whittington Hospital	
Nottingham City Hospital	William Harvey Hospital	
Ormskirk District General Hospital	Wishaw General Hospital	
Peterborough City Hospital	Worcestershire Royal Hospital	
Pilgrim Hospital	Worthing Hospital	
Pinderfields General Hospital	Wrexham Maelor Hospital	
Poole Hospital	Wythenshawe Hospital	
Prince Charles Hospital	Yeovil Women's Hospital	
	York Hospital	
	Ysbyty Gwynedd District General Hospital	

Current Study Reminders

New study STARTED – Haemophagocytic Lymphohistiocytosis (HLH)

The HLH study started on 1st October 2024 and is due to run for 5 years (ending 30th September 2029).

Please report any pregnant or recently pregnant women (<6 weeks since the end of pregnancy) with a diagnosis or suspected diagnosis of haemophagocytic lymphohistiocytosis (HLH) or macrophage activation syndrome (MAS).

Final call for data collection forms!

The Biological Agents in pregnancy study has now ended. As some of you may be aware, we are now working through data queries. With this in mind, please keep an eye out for any emails from us asking for missing data or requesting clarification on possible data errors.

In addition, please could you also check that no cases have been missed and notify us as soon as possible if any cases are identified.

Here is a reminder of the case definition:

All pregnant women identified as having taken one of the following biological agents for the indication of treatment of an inflammatory disorder in pregnancy:

Natulizumab, Duplilimab, Mepolizumab, Ustekinumab, Belimumab, Rituximab, Secukinumab, Ixekizumab, Tocilizumab, Canakinumab, Anakinra, Sarilumab, Abatacept, Guselkumab, Omalizumab, Dupilumab, Mepolizumab, Vedolizumab, Rinsakizumab, Anifrolumab, and 'other' novel biological agent (**excluding Etanercept, Adalimumab, Infliximab, Certolizumab and their biosimilars**).

Please note that to be included in the study, women need to have delivered on or after 1st May 2022 and before 31st October 2024.

Peripartum Hysterectomy is a case-control study – what does that mean?

A case-control study means that for every case reported, we will also request two control forms.

The controls are the **TWO** women who delivered immediately **BEFORE** the case. Each control will be labelled with the original case ID followed by either 1 or 2. Please complete separate control forms for each control.

If you have any questions about how to identify the controls then please do not hesitate to contact us at ukoss@npeu.ox.ac.uk.

Please remember...

- To keep a record of the UKOSS IDs with the corresponding patient details for all the cases you report
- To inform the UKOSS Team and pass on your case list to another reporter if you change roles or retire

Star Reporters

This newsletter we would like to thank **Gillian Lyons, New Cross Hospital**, for returning the first set of completed data collection forms (case and controls) for the peripartum hysterectomy study and **Alicia St Louis, Whittington Hospital**, for being the first to report in 2025.

Your edible goodies will be in the post very soon!



Case Report Summary for Studies up until the end of December 2024

Study	Actual number of reported cases	Data collection forms returned	Number of forms returned that were found to be not cases / reported in error	Data Collection forms returned that are confirmed cases	Expected Number of Confirmed Cases
Amniotic Fluid Embolism	437	418	106	312	239
Biologic Agents in Pregnancy (now ended)	552	431	184	247	752
HLH	3	2	0	2	1
Long-term non-invasive ventilation in pregnancy	88	63	14	49	88
Peripartum hysterectomy - CASES	76	36	4	32	100
Peripartum hysterectomy – CONTROLS	N/A	58	N/A	N/A	N/A
Severe Respiratory Virus – RECOVERY & REMAP-CAP trials	33	33	32	1	139
Thrombotic Microangiopathy Associated Pregnancy Acute Kidney Injury (now ended)	42	32	12	20	479
Transabdominal cerclage	46	36	12	24	75

The UKOSS Steering Committee have a Vacancy!

There is currently a vacancy on the UKOSS Steering Committee for a **Welsh Representative**.

The UKOSS Steering Committee meets three times a year and is responsible for considering applications for new studies on the UKOSS programme and monitors the progress of ongoing studies.

For more information about the role, please see

www.npeu.ox.ac.uk/ukoss/news/2209-applications-sought-for-welsh-representative-on-the-ukoss-steering-committee



If you would like to apply, please submit a two page CV and a short covering letter stating why you would like to undertake the role to UKOSS at ukoss@npeu.ox.ac.uk.

