



Royal College of
Obstetricians
and Gynaecologists

NEWSLETTER 72 - October 2024

Breast cancer in pregnancy – results published!

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



From October 2015 – September 2017, 84 women (incidence of 5.4/100,000 maternities, 95% CI 4.37, 6.70) received a breast cancer diagnosis during pregnancy (women diagnosed pre-pregnancy or with a recurrence were excluded). 11% of women had undergone in vitro fertilisation (IVF) which is higher than the estimated 2.6% IVF pregnancies in the UK at that time. 30 women (36%) underwent surgery during pregnancy and 37 (44%) received chemotherapy. Three women had major maternal morbidity during pregnancy, two women died and there were two perinatal deaths.

The study concluded that the incidence of newly diagnosed breast cancer in pregnancy in the UK is comparable to that reported in other countries. The higher proportion of IVF pregnancies amongst pregnant women diagnosed with breast cancer may be explained by relatively advanced maternal age, but requires further investigation. Management of breast cancer varies considerably and despite generally good short-term outcomes for both mothers and babies, a larger prospective study is required to allow longer-term follow-up.

The full paper can be found here <https://openresearch.nihr.ac.uk/articles/4-40>.

Reference: Hardy C, Brand A, Jones J et al. The UK Breast Cancer in Pregnancy (UKBViP) Study. Incidence, diagnosis, management and short-term outcomes of breast cancer first diagnosed during pregnancy in the United Kingdom: A population-based descriptive study. NIHR Open Research 2024, 4:40.



Vasa Praevia study results!

The results of the vasa praevia study have been published in NIHR Open Research.

Between December 2014 and November 2015, 51 women met the case definition (incidence of 6.64/100,000 maternities, 95% CI 5.08-8.73) which was lower than anticipated. 10 out of 198 units reported they had a formal screening programme for vasa praevia and one of these 10 units identified 25% of the antenatally diagnosed cases. 28 women were diagnosed during the antenatal period and 23 were diagnosed during labour or after giving birth. There were no perinatal deaths or hypoxic ischaemic encephalopathy (HIE) among the women who had vasa praevia diagnosed or suspected antenatally. 24 of the women diagnosed antenatally were hospitalised at a median gestation of 32 weeks and caesarean section was planned at a median gestation of 36 weeks. Of the 23 women who were diagnosed postpartum, the perinatal mortality rate was 37.5%, with 47% of survivors developing HIE.

The study concluded that there was a higher perinatal morbidity and mortality rate for those who were not diagnosed antenatally, however there were good outcomes when vasa praevia was diagnosed during pregnancy.

The full paper can be found here <https://openresearch.nihr.ac.uk/articles/4-49>.

Reference: Attilakos G, David AL, Tunn R et al. Incidence and outcomes of vasa praevia in the United Kingdom. NIHR Open Research 2024, 4:49.



THIS MONTH

- Welsh Representative wanted for Steering Committee!
- New study starting – HLH



Hospital Monthly Reporting Rates over Six Months (March 2024 - August 2024)

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

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

New study starting – Haemophagocytic Lymphohistiocytosis (HLH)

HLH is a rare and often life threatening condition characterised by the coexistence of immune dysregulation and unchecked inflammation. Primary HLH is genetic in origin and often diagnosed in infancy. Secondary HLH is the form typically seen in adults, and arises secondary to a trigger condition such as an infection, malignancy or rheumatic disease. Historically, HLH associated with an underlying rheumatic disease has been termed Macrophage Activation Syndrome (MAS) but modern guidelines advocate that all forms of this disease are now referred to as HLH, regardless of the underlying driver. HLH is clinically associated with fever, cytopenia, liver dysfunction, hepatosplenomegaly, hypertriglyceridaemia and hyperferritinaemia and treatment involves the use of immunosuppressive agents.

MBRRACE-UK maternal mortality reports 2013-2021 documented 8 maternal deaths secondary to HLH, however the incidence of the women who survived is unknown.

Objective: Determine the incidence of HLH in the pregnant population, describe the main aetiologies of HLH in pregnancy, document the outcomes for both mother and fetus/neonate and describe the treatments used.

Surveillance period: 1st October 2024 – 30th September 2029 (5 year study)

Case definition: Any pregnant or recently pregnancy (<6 weeks since the end of pregnancy) woman with a diagnosis or suspected diagnosis of haemophagocytic lymphohistiocytosis (HLH) or macrophage activation syndrome (MAS).

Please note: All reporters will be emailed the short protocol and case definition, however please contact the team at ukoss@npeu.ox.ac.uk if you have any queries. The study details will also be available on the website at www.npeu.ox.ac.uk/ukoss/current-surveillance.

Final call for data collection forms!



The Thrombotic Microangiopathy Associated Pregnancy Acute Kidney Injury study has now ended. We would be very grateful if you could return any outstanding data collection forms or data queries over the next few months.

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 who meet the following criteria:

A rise in serum creatinine to >200mmol/l AND platelet count <150x10⁹ L AND at least one evidence of haemolysis (fragments on blood film, haptoglobin below lower limit of normal or lactate dehydrogenase above the upper limit of normal)

Excluded: All women established on renal replacement therapy prior to the acute AKI episode.

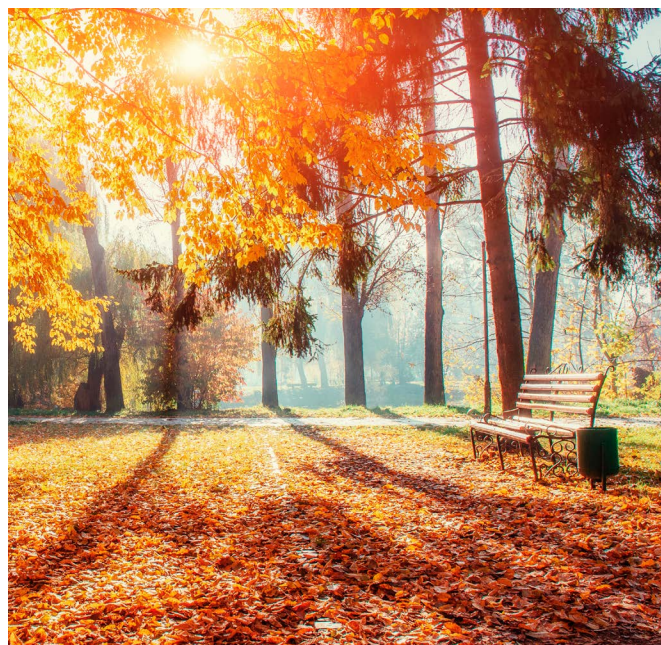
Study finishing soon!

Please be aware that the **Biologics** study is ending this month

Star Reporters

This newsletter we would like to thank **Johnson Amu, Victoria Hospital (Blackpool)**, for being the first to report a case of peripartum hysterectomy and **Nikolaos Chados, Ormskirk District General Hospital**, for catching up with reporting.

Your edible goodies will be in the post very soon!



How do I select control forms?

The peripartum hysterectomy study is a case/control study which means that for every case reported, we will request two control forms.

The control forms should be the **TWO** women who delivered immediately **BEFORE** the case. Each control will be labelled with the original case ID then either 1 or 2.

Example

Log of Births		
Order of Births	Date and time of delivery	
1	30/09/24 @ 20:00	✗
2	30/09/24 @ 23:45	✓
3	01/10/24 @ 05:00	✓
4 *Had peripartum hysterectomy*	01/10/24 @ 07:00	
5	01/10/24 @ 12:30	✗
6	01/10/24 @ 15:00	✗

Case Report Summary for Studies up until the end of August 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	424	402	91	311	236
Biologic Agents in Pregnancy	495	394	164	230	726
Long-term non-invasive ventilation in pregnancy	74	51	13	38	76
Peripartum hysterectomy – CASES	24	6	1	5	25
Peripartum hysterectomy – CONTROLS	N/A	6	N/A	N/A	10 controls requested
Severe Respiratory Virus – RECOVERY trial	33	33	32	1	126
Thrombotic Microangiopathy Associated Pregnancy Acute Kidney Injury	42	32	12	20	476
Transabdominal cerclage	36	20	12	8	47

Come and join the UKOSS Steering Committee!

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.

The deadline for applications is **6th January 2025**.



Gentle Reminders

- Before returning a data collection form, **please check that all fields are completed**. If the requested information is unavailable, please note this in the final section of the form.
- If the UKOSS team find incomplete questions during data entry (we call them data queries), we will email the reporter to request the missing information.
- **Please keep a record of the cases you've reported and the linked patients** and if you change roles or retire, please pass on your case list to another reporter.

Taking these steps will enable us to resolve queries in a timely manner and meet the primary aims of our studies.

GMC Revalidation and NMC Continuing 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.

