Royal College of Obstetricians and Gynaecologists

UKOSS

UK Obstetric Surveillance System

NPEU

80 **NEWSLETTER 80** - October 2026 80

Two new conditions being added to the UKOSS programme!

Endocrine related neoplasia syndrome in pregnancy

Multiple endocrine neoplasia type 1 (MEN1), multiple endocrine neoplasia type 2/3 (MEN2/3) and Von Hippel Lindau (VHL) are hereditary endocrine tumour syndromes that are most frequently identified through genetic testing of at-risk family members. Theses genetic syndromes are rare but cumulatively are estimated to affect 100 pregnancies per year in the UK. Small studies and anecdotal case reports suggest increased maternal and neonatal complications in pregnancies affected by these genetic syndromes, but at present there are no guidelines for the management or surveillance of pregnancy for women with MEN1, MEN2/3 and VHL. This study will enable us to determine the incidence of MEN1, MEN2/3 and VHL in pregnancy and describe the management of both maternal and neonatal outcomes.

Surveillance period: 1st October 2026 – 30th September 2028

Case definition: All pregnant women identified as having a genetic diagnosis of MEN1*, MEN2/3** (former name MEN2B) or VHL***

* Multiple endocrine neoplasia type 1 (caused by an inherited pathogenic variant in the MEN1)

** Multiple endocrine neoplasia type 2 or 3 (caused by inherited pathogenic variants in the RET gene)

*** Von Hippel Lindau syndrome (caused by inherited pathogenic variants in the VHL gene)

Pregnancy Outcomes of Cardiothoracic Transplant Recipients in the UK

Worldwide, in the eras spanning 1992-2000, 2001-2009 and 2010-2018, there has been a growth in the number of heart transplants being performed in women of childbearing age; 2509, 3142 and 3578 respectively. Of all UK heart transplants performed in 2022-23 (n=185) 32% were female (n=59), and 29 if these women (49%) were of reproductive age.

Advances in surgery, perioperative care and immunosuppression have improved long-term outcomes for patients after cardiac transplantation. Worldwide, the current median survival conditional to surviving the first-year post heart transplant (HT) is 14.8 years for women and 13.6 years for men, with overall survival at one year 86%. Experience from major cardio-obstetric centres in the UK suggests that pregnancies in cardiac transplant recipients are increasing in line with these gains in healthy survival. Recently published data from the International Society for Heart and Lung Transplantation (ISHLT) registry has shown that female HT recipients of childbearing age (15/45 years) have a favourable overall survival, however this varies according to underlying pathology.

In view of the advances in cardiothoracic transplantation, the contemporary international consensus statement and greater understanding of post-transplant outcomes in women of child bearing age, there is a renewed and important need to begin to collect prospective UK data to optimise pre-pregnancy counselling and perinatal management for this rare but high-risk patient group.

Surveillance period: 1st December 2026 – 30th November 2029

Case definition: Any pregnant woman in the UK with a history of cardiothoracic organ transplantation. This includes recipients of a heart transplant, lung transplant or heart and lung transplant.

Please note: All reporters will be emailed the short protocols and case definitions for both these studies, 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*** shortly.

THIS MONTH

- 21 years of UKOSS
- Group B Strep - BPSU study

Hospital Monthly Reporting Rates over SIX MONTHS (Mar 2026 – Aug 2026)

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

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

Arrowe Park Hospital
Barnsley Hospital
Bassetlaw Hospital
Calderdale Royal Hospital
Chelsea & Westminster Hospital
Daisy Hill Hospital
Doncaster Royal Infirmary
Dumfries & Galloway Royal Infirmary
Manor Hospital (Walsall)
Nobles Hospital (Isle of Man)
Northwick Park Hospital
Royal Berkshire Hospital
Royal Bolton Hospital
Royal Oldham Hospital
Scarborough Hospital
Tameside General Hospital
The Portland Hospital
Ulster Hospital
University Hospital of North Midlands
Yeovil Women's Hospital
Darlington Memorial Hospital
Kettering General Hospital
Lancashire Teaching Hospitals (Royal Preston Hospital)
St Mary's Hospital (London)
University Hospital of North Durham
York Hospital
Furness General Hospital
John Radcliffe Hospital
Royal Jubilee Maternity Service
St Helier Hospital
Caithness General Hospital
James Cook University Hospital
Princess Royal University Hospital
Queen Elizabeth University Hospital (Glasgow)
Worcestershire Royal Hospital

Birmingham Women's Hospital
Princess Royal Hospital (Haywards Heath)
Royal London Hospital
Royal Sussex County Hospital
Russells Hall Hospital
St Richard's Hospital
The Hillingdon Hospital

Star Reporters

We would like to thank **Anne-Marie Whiting** from **Torbay Hospital** for supporting UKOSS as a reporter since UKOSS began and **Saskia Walsh** from **West Middlesex Hospital** for getting reporting back on track.

Your edible goodies will be in the post very soon!

Watch this space

We are hoping to add two new conditions to the UKOSS programme in the next few months – **Severe Maternal Sepsis** and **Delivery of Twin pregnancies between 14+0 and 23+6 weeks** – so please keep an eye on your emails and the website for further information.

21 years of the UK Obstetric Surveillance System (UKOSS)

The MBRRACE-UK virtual conference launching the 'Saving Lives, Improving Mothers' Care' 2026 Report was held on 10th September and UKOSS had a dedicated session in the programme to celebrate it's 21st anniversary. The UKOSS presentations were all well-received and highlighted the impact and value of the UKOSS programme.

The following topics were discussed and we will release summaries of these in upcoming newsletters. Watch this space!

- **The impact of UKOSS**
- **Peripartum hysterectomy**
- **Haemophagocytic Lymphohistiocytosis (HLH)**
- **Biologics in pregnancy - the MAMA Study**
- **Preventing Severe Maternal Morbidity and mortality through a national programme of interventions - PRiSMM**
- **Extremely preterm prelabour rupture of membranes and the PROMAT trial**
- **Diagnosis of Pulmonary Embolism in Pregnancy - the DiPEP study**

If you have any queries regarding the UKOSS presentations at the MBRRACE-UK conference then please do get in touch at ***ukoss@npeu.ox.ac.uk***.

Group B Strep – BPSU study

On 1st October 2026, the British Paediatric Surveillance Unit (BPSU) will be launching thirteen months enhanced surveillance of invasive Group B Streptococcal disease in infants aged up to 90 days in the UK and Ireland. The BPSU have sought the assistance of UKOSS as detailed below, although we anticipate the impact on UKOSS reporters to be minimal.

Cases will be identified through monthly BPSU reporting by paediatricians; however, in some cases the reporting paediatrician may not have access to complete information regarding the pregnancy, maternal risk factors, labour, delivery or intrapartum management. In these circumstances, the study co-ordinator may ask the local UKOSS reporter to assist in obtaining supplementary information from the mother's clinical records which the paediatrician will then use to complete the study proforma. Pleae note that UKOSS reporters with not be required to identify or report cases and will not be required to compete any data collection forms. As mentioned above, we anticipate that the impact on UKOSS reporters will be minimal as assistance will only be sought for a small number of cases.

The study will be led by a team from City St George's, University of London in collaboration with UKHSA. The study is funded by Group B Strep Support (***https://gbss.org.uk/***). If you have any questions regarding the study, please contact the study co-ordinator, Andy Young (***ayoung@citystgeorges.ac.uk***).



Primary Ciliary Dyskinesia (PCD) extension!

Please note that the end date for the PCD study has been extended to **31st October 2027**

Case Report Summary for Studies up until the end of August 2026

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	462	445	173	273	260
HLH*	23	18	4	14	6
Peripartum hysterectomy - CASES (study now ended)	322	274	13	261	425
Peripartum hysterectomy – CONTROLS	N/A	496	N/A	N/A	N/A
Primary Ciliary Dyskinesia	16	11	6	5	59
Severe Respiratory Virus – RECOVERY & REMAP-CAP trials	37	37	35	2	227

*Haemophagocytic Lymphohistiocytosis (HLH) or Macrophage Activation Syndrome (MAS)



We would like to thank all UKOSS reporters who have already replied to our data queries/ missing data requests for the Peripartum Hysterectomy study. We realise that for some units there have been a large number of requests and we appreciate everyone's support.

We would like to ensure that the dataset is as complete as possible before we commence final analysis, therefore if you also have any outstanding data collection forms to return, we would be very grateful if you could forward them to us as soon as possible.

Come and join the UKOSS Steering Committee!



Applications are still open for a Scottish Rep 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***. Deadline for applications is 4th January 2027. More information about the Steering Committee can be found on our ***website***, but please do contact us at ***ukoss@npeu.ox.ac.uk*** if you have any questions.

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 sent to you.



NPEU

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Email: *ukoss@npeu.ox.ac.uk* **Web:** *www.npeu.ox.ac.uk/ukoss*

Admin team: 01865 617764

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