





64

NEWSLETTER 64 - August 2022





Join our first UKOSS Study Day!

We are excited to announce that on 29th November 2022 we will be holding our first ever UKOSS Study Day! This half-day event will be held virtually and will be free to attend. We will highlight clinical updates from our most recent and high profile studies, showing the vital contribution our reporters make to research into rare conditions. The day will also be an opportunity for us to discuss applications for new studies and explain how we conduct research using UKOSS. All are welcome, reporters as well as those who are not UKOSS reporters but are interested in our research, although initial priority booking will be given to reporters. Keep an eye on our website for details about how to attend: www.npeu.ox.ac.uk/ukoss/news

If you are an obstetric physician, or you are based in Wales or Northern Ireland, we would like to hear from you!

There are still three positions available on the Steering Committee: obstetric physician, and representatives for Wales and Northern Ireland (anaesthetist, midwife or obstetrician currently working for NHS Wales or HSC Northern Ireland).

To find out more and apply, please visit our website: www.npeu.ox.ac.uk/ukoss/news. If you have any questions please contact us: ukoss@npeu.ox.ac.uk. We look forward to hearing from you!

Meet our New UKOSS Steering Committee Members...

In the spring we welcomed five new members to our Steering Committee: Vinnie Sodhi (representative for the Obstetirc Anaesthetists' Association), Joyce Adu-Amankwah (midwife representative), Julie Grindey (midwife representative), Akila Anbazhagan (obstetrician representative) and Tannice Hemming (PPI representative).

We would also like to congratulate Claire Williams and David Churchill who are now Co-Chairs of the Steering Committee. Our sincere thanks to Kim Hinshaw for his contribution as Chair for 6 years, and also to Susanna Stanford for her invaluable dedication as PPI representative since 2016.

Meet some of our new members below and look out for more member profiles in our next newsletter!



Joyce Adu-Amankwah completed her midwifery education in 2004. She is a senior midwife, having previously worked as a Labour Ward Coordinator. Joyce's current role is a Specialist Haemoglobinopathies Midwife at St. Georges University Hospital NHS Foundation Trust. She provides specialist antenatal care for pregnant women who have sickle cell and thalassaemia diseases. Joyce also offers genetic counselling for pregnant women and couples at risk of having babies affected by the major conditions, screening the biological father of the unborn baby, and offering prenatal diagnostic testing (PND) in supporting the decisions the parents make about their pregnancies.

Joyce received the Iolanthe Midwifery Trust Midwives Award in 2019 and was shortlisted for BAME Health and Social Care Award in 2022. She is part of the team conducting the TAPS2 (Transfusion Antenatally in Pregnancy for pregnant Women with Sickle Cell Disease) Trial. Joyce is passionate about improving maternity care and delighted to be part of the UKOSS Steering Committee.

Julie Grindey is a research midwife at Wirral University Teaching Hospital Foundation Trust. She has been a research midwife for 10 years and currently she mainly recruits to the Reproductive Health portfolio. During the pandemic she played a key role in submitting data to the UKOSS COVID-19 in Pregnancy study. Julie is also the Vice-Chair of North West Greater Manchester West Research Ethics Committee. She is really looking forward to being part of the steering committee into the study of rare obstetric disorders.





Dr Akila Anbazhagan has been a consultant obstetrician for the past 10 years and currently works at St Mary's Hospital, Wythenshawe (Manchester University NHSFT). Her special interests include maternal-fetal medicine and high risk obstetrics. Akila's clinics provide care for women with diabetes and endocrine disorders, cystic fibrosis and asthma. She also has vast experience of maternity governance and risk.

Akila is Clinical Lead of the Greater Manchester and Eastern Cheshire (GMEC) Local Maternity System and she is also co-chair of the GMEC Black and Asian maternity advisory group. She has been a UKOSS reporter for the past 8 years and is now looking forward to contributing towards supporting research and understanding the rare conditions affecting pregnancies.

Tannice Hemming has worked alongside her local NHS in Kent and Medway since she became a parent and is now a mum of three. As a Maternity Voices Partnership Chair, she bridged the gap between service users (birthing women and people, plus their families) and clinicians, to co-produce improvements in maternity care. She has also volunteered as a breastfeeding peer supporter.



Two of Tannice's proudest achievements include co-authoring a module of Health Education England's E-learning on Trauma Informed Care and the Kent and Medway Bump, Birth and Beyond Maternity website. A member of several maternity steering groups and panels, projects Tannice has collaborated on include several focusing on maternal mental health, neonatal care, maternal weight and chronic illness.

Case Report Summary for Studies up until the end of July 2022

Study	Actual number of reported cases	Data collection forms returned (%)	Expected number of confirmed cases
Amniotic Fluid Embolism	294	282 (96)	210
Antithrombin/Protein C Deficiency	84	68 (81)	374
Biologic Agents in Pregnancy	32	7 (22)	76
Fontan and Pregnancy	36	27 (75)	135
New Therapies for Influenza	2	1 (50)	130
Pregnancy following Bone Marrow Transplant	36	29 (81)	130
Pregnancy in Women with Known Cardiomyopathy	66	52 (79)	232
Re-exploration after Caesarean Section	223	160 (72)	269
Severe Respiratory Virus – RECOVERY trial	1	0(0)	17
Thrombotic Microangiopathy Associated Pregnancy Acute Kidney Injury	5	5 (100)	173

Study Changes

Our *New Therapies for Influenza* study has been extended until 30th April 2023.

Please also note that the *Thrombotic Microangiopathy Associated Pregnancy Acute Kidney Injury* (TMA AKI) study has also been extended, until 30th June 2023.

There has also been a change to the study definition for the TMA AKI study: the threshold for the rise in serum creatinine has been lowered to >200 mmol/l. Please see our website for the full definition: www.npeu.ox.ac.uk/ukoss/current-surveillance.

Studies Recently Closed

Three of our studies have closed for reporting recently:

- · Fontan and Pregnancy
- · Re-exploration after Caesarean Section
- · Antithrombin/Protein C Deficiency in Pregnancy

The study investigators will soon begin to analyse the data for these studies, so please ensure that you send through any outstanding data collection forms as soon as possible.

Star Reporters

We would like to thank all of our reporters for their continued hard work – without you, our research would not be possible. As a small gesture of our appreciation, the following star reporters have received some edible goodies:

Monica Alang, of Watford General Hospital, and **Bridget Tuohy**, of Southmead Hospital, for their extremely hard work completing a large number of data collection forms. **Stephanie Keene**, of Royal London Hospital, for her very prompt completion of forms.

Got an idea for a study? Get in touch with us!

We are welcoming applications for new UKOSS studies. For more information about how to apply, please visit www.npeu.ox.ac.uk/ukoss/research-platform/survey-applications or feel free to contact us at: ukoss@npeu.ox.ac.uk or 01865 617764

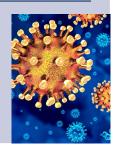
New study starting soon: Severe Pyelonephritis in Pregnancy

Keep an eye out for a new UKOSS study into Severe Pyelonephritis in Pregnancy. The study is expected to begin in September, we will be sending out all the relevant information a month prior to the start date.

Our COVID-19 in Pregnancy Research Comes to an End...

Our COVID-19 in Pregnancy study represented an enormous effort on the part of all of our reporters. In total, **19,347** cases were reported and **18,381** data collection forms were returned **(95%)**. We will continue to collect outstanding data (including delivery/outcome data) until October, so please do send through any outstanding data as promptly as possible.

Our latest COVID-19 paper "Severity of maternal SARS-CoV-2 infection and perinatal outcomes during the Omicron variant dominant period: *UK Obstetric Surveillance System national cohort study*" will be published in BMJ Medicine shortly, but in the meantime is available as a *pre-print*.



A Refresher in UKOSS Reporting

How does reporting to UKOSS work?

Registered reporters receive an email on the first of every month asking them to report the number of eligible cases in the preceding month for our *current surveillance studies*. The eligibility criteria for all of our studies can be found on our website, and we in the UKOSS team are always happy to help with queries. For each case that is reported, we then email through the case ID number that should be used and the data collection form for completion.

What about if there are no eligible cases at my hospital that month?

It is very important that you return a 'nil report' when there have been no eligible cases, so that we can calculate the prevalence of the condition, so please ensure you enter a zero in all the relevant boxes and submit.

Who should be responsible for UKOSS reporting at my hospital?

Different types of staff and teams can report to UKOSS; the responsibility does not need to fall to just one team or person. The way UKOSS reporting is delegated at a particular hospital will depend on how that hospital is structured, but the most common types of reporter are: midwife, research midwife, obstetrician, anaesthetist, and perinatal risk staff. Having a combination of different types of reporter at a hospital helps to ensure that all eligible cases are captured.

All reporters receive the monthly reporting email. Completion of data collection forms can be delegated to other staff, as long as the reporter checks and signs off the form.

Do you keep a record of the patient details of each case?

No, we at UKOSS are not permitted to receive patient details. For this reason, it is vital that each hospital keeps a log of the cases they have reported, with the patient details.

Many hospital staff members helped with reporting during the pandemic. We will soon be in touch with all hospitals to ensure we have the correct reporters registered now. Staff who previously only reported for the COVID study should now let us know if they wish to become a general UKOSS reporter or if we should remove them from our records. If you are aware that you need to update us about the reporters at your hospital please get in touch with us.



Hospital Monthly Reporting Rates: March - May 2022

3 months reported, 2 months reported, 1 month reported, 0 months reported

Aberdeen Maternity Hospital Airedale General Hospital Altnagelvin Area Hospital

Aneurin Bevan University Health Board

Antrim Hospital Arrowe Park Hospital Basildon Hospital **Bedford Hospital**

Birmingham Heartlands Hospital Birmingham Women's Hospital Borders General Hospital **Bradford Royal Infirmary** Broomfield Hospital Caithness General Hospital Calderdale Royal Hospital Causeway Hospital

Chesterfield & North Derbyshire Royal Hospital

City Hospital (Birmingham) Colchester General Hospital 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

Dumfries & Galloway Royal Infirmary

Epsom General Hospital Forth Valley Royal Hospital George Eliot Hospital

Glan Clwyd District General Hospital Gloucestershire Royal Hospital

Good Hope Hospital

Guy's and St Thomas' Hospital Harrogate District Hospital Hinchingbrooke Hospital Homerton University Hospital

Hull Royal Infirmary

James Cook University Hospital Jersey General Hospital Kettering General Hospital King's Mill Hospital Kingston Hospital

Lancashire Women and Newborn Centre

Leeds General Infirmary Leighton Hospital Lincoln County Hospital Lister Hospital

Liverpool Women's Hospital Luton & Dunstable Hospital Manor Hospital - Walsall Medway Maritime Hospital Musgrove Park Hospital **New Cross Hospital**

Ninewells Hospital & Medical School

Nobles Hospital, Isle of Man

Norfolk & Norwich University Hospital

North Devon District Hospital

Northumbria Specialist Emergency Hospital

Northwick Park Hospital Nottingham City Hospital

Ormskirk District General Hospital Peterborough City Hospital

Pilgrim Hospital

Prince Charles Hospital Princess Alexandra Hospital Princess Anne Hospital

Princess of Wales Hospital Queen Alexandra Hospital

Queen Elizabeth Hospital (Woolwich) - Woolwich,

London

Queen Elizabeth the Queen Mother Hospital

Queen's Medical Centre Raigmore Hospital Rosie Maternity Hospital

Rotherham District General Hospital Royal Albert Edward Infirmary Royal Alexandra Hospital Royal Berkshire Hospital Royal Cornwall Hospital Royal Derby Hospital

Royal Devon & Exeter Hospital

Royal Free Hospital Royal London Hospital Royal Surrey County Hospital Royal Sussex County Hospital Royal United Hospital Royal Victoria Infirmary Russells Hall Hospital

Simpson Centre for Reproductive Health

Singleton Hospital

South West Acute Hospital Southend University Hospital Southern General Hospital

St Helier Hospital

St James's University Hospital

St John's Hospital

St Mary's Hospital (Isle of Wight) - Newport St Mary's Hospital (Manchester) - Manchester

St Michael's Hospital St Peter's Hospital St Richard's Hospital Stoke Mandeville Hospital Sunderland Royal Hospital The Great Western Hospital The Jessop Wing

The Portland Hospital The Tunbridge Wells Hospital

Torbay Hospital Ulster Hospital

University College Hospital University Hospital Lewisham

University Hospital of Coventry & Warwickshire University Hospital of North Midlands - Stoke-on-

Trent

University Hospital of North Tees Victoria Hospital - Blackpool Victoria Hospital - Kirkcaldy Warrington Hospital Warwick Hospital Watford General Hospital West Cumberland Hospital

West Middlesex University Hospital

Western Isles Hospital Wexham Park Hospital

Whipps Cross University Trust Hospital

Whiston Hospital Whittington Hospital Wishaw General Hospital Wrexham Maelor Hospital Yeovil Women's Hospital

York Hospital

Ysbyty Gwynedd District General Hospital

Ayrshire Maternity Unit

Barnet Hospital (Royal Free London NHS

Foundation Trust) Bronglais Hospital East Surrey Hospital Glangwili General Hospital Hereford County Hospital James Paget University Hospital

King's College Hospital

Lancashire Teaching Hospitals (Royal Preston

Hospital)

Leicester Royal Infirmary Pinderfields General Hospital

Poole Hospital

Princess Elizabeth Hospital (Guernsey) Princess Royal Hospital (Haywards Heath) -Haywards Heath

Princess Royal Hospital (Telford) - Telford Princess Royal University Hospital Queen Charlotte's and Chelsea Hospital Queen Elizabeth Hospital (Gateshead) -

Gateshead Queen's Hospital (Burton) - Burton-on-Trent

Royal Hampshire County Hospital Royal Jubilee Maternity Service Royal Lancaster Infirmary Scunthorpe General Hospital Southmead Hospital

St George's Hospital Stepping Hill Hospital Tameside General Hospital The Hillingdon Hospital West Suffolk Hospital Worcestershire Royal Hospital

Worthing Hospital Wythenshawe Hospital Barnsley Hospital Daisy Hill Hospital

East Sussex Healthcare NHS Trust (Conquest

Hospital) **Ipswich Hospital** John Radcliffe Hospital

North Middlesex University Hospital Princess Royal Maternity Hospital Salisbury District Hospital

St Mary's Hospital (London) - London Basingstoke and North Hampshire Hospital Bassetlaw District General Hospital

Chelsea & Westminster Hospital **Darlington Memorial Hospital Doncaster Royal Infirmary** Frimley Park Hospital Furness General Hospital Leicester General Hospital

Macclesfield District General Hospital

Milton Kevnes Hospital Newham General Hospital

North Manchester General Hospital Northampton General Hospital

Queen Elizabeth Hospital (Kings Lynn) - Kings

Lynn Queen's Hospital (Romford) - Romford, Essex

Royal Bolton Hospital Royal Oldham Hospital Scarborough Hospital

University Hospital of North Durham University Hospital of Wales William Harvey Hospital - East Kent





