



# RePHyNe

Registry of Pulmonary Hypertension in Neonates

## July 2025 Newsletter

Issue number: 2

Welcome to the second edition of the RePHyNe quarterly newsletter.

If you would like your site to be involved with RePHyNe but haven't yet signed up you can go to our website - <https://rephyneregistry.com> - and click on the Join the Registry button.

As always, we would like to showcase relevant neonatal pulmonary hypertension (PH) content from readers. If you have anything you want featured you can email [rephyneregistry@lwh.nhs.uk](mailto:rephyneregistry@lwh.nhs.uk)



### RePHyNe Project



We would like to thank every site that is recruiting participants, going through the set-up process or has let us know that they are interested in being part of the registry. Every patient's data that is added to the registry will help us to increase our knowledge about neonatal pulmonary hypertension.

We are currently opening UK sites but are still welcoming Expressions of Interest from international neonatal units - you can find the link to the form in the section above. We plan to start opening international sites in late 2025.

### Meet the Team: NIHR Research Nurses

RePHyNe is on the NIHR Research Delivery Network (RDN) portfolio which means that units can potentially get support from their Research Nurses. At Liverpool Women's Hospital we have three of these nurses helping with RePHyNe - we sat down with them to talk about what their job involves.

#### What help can you offer with RePHyNe and other portfolio studies?

We highlight potential participants to the clinical team, approach participants (or parents if the participant is a child), gain consent if eligibility has been confirmed and help with data collection. In essence, research nurses play a vital role in bridging the gap between research and clinical practice.

A typical day involves a mix of clinical duties and administrative tasks, all focused on supporting clinical trials and research studies. These include screening daily for potential participants, approaching parents with the study specific information leaflet, collecting data for the trials and daily monitoring of participants, whilst also reporting any adverse events or unexpected findings to the research centre. This is all performed whilst ensuring patient safety.

#### What does your typical day look like?

#### What is your favourite part of the job?

Working autonomously, therefore having a stronger sense of empowerment and freedom whilst also having the opportunity to contribute to medical advancements and improve patient care. This also advances my knowledge, and I feel like I am making a difference. I also enjoy providing emotional support and education to families participating in studies during their time on NICU.

I had worked on the neonatal unit for over a decade when a research nurse secondment was advertised and I got the job. This turned into a permanent role due to the expansion of clinical research trials and studies being set up on the neonatal unit. I have now been in the research nurse role for over 12 years. It has been both enjoyable and challenging.

#### How did you start working in research?

#### How do research nurses help clinical teams?

They provide support by acting as a bridge between clinical care and research initiatives. This involves training and supporting the NICU team on study specific requirements. They also help to integrate research findings into clinical practice to improve patient care.



## Developing a Neonatal Pulmonary Hypertension Core Outcome Set (NeoPH COS) Delphi round 2 to open shortly

Results from the first round of the Delphi survey are being analysed and the results of the qualitative conversations with parents and/or guardians are being written up. Once that is complete, round two will open. This will further narrow down the responses, which will then go to a consensus meeting to determine the final outcome set.

### RePHyNe is now part of the NIHR Associate Principal Investigator (PI) scheme



The Associate PI scheme is a six-month in-work training opportunity for healthcare care professionals who are looking to become involved in research. Supported by their local RePHyNe PI they will take part in all study activities, working through a set list of tasks that give them real-life experience of being a study PI. At the end of the six months, if all activities have been signed off, a certificate will be issued by NIHR which can be added to their training portfolio. If you are interested in this scheme, more details can be found on the NIHR website: [Associate PI Scheme Frequently Asked Questions \(FAQs\) | NIHR](#)

### RePHyNe has two abstracts accepted for the 2025 Joint European Neonatal Societies (JENS) Congress

Dr Aikman will be presenting on 'Development of an Echocardiography Dataset in Neonatal Pulmonary Hypertension: An International Consensus Study' and 'A Systematic Review of Clinical Outcomes in Neonatal Pulmonary Hypertension'. If you are attending, make sure to keep an eye out for her.

### MaRPHyNe Given Green Light to Begin Recruitment

The Magnetic Resonance Imaging in Neonates with Pulmonary Hypertension (MaRPHyNe) study has received Sponsor approval to begin participant recruitment. Researchers will use MRI scans of the heart and brain to explore whether pulmonary hypertension affects the structure and function of these organs in affected neonates.

## RePHyNe Sites and Recruitment

At the time of publication we have four UK sites open and recruiting participants. Between them they have added data for eight patients to the registry. Additionally, there are another nineteen sites going through set-up, with three of them expected to begin recruitment in the next few weeks.

## Frequently Asked Questions

Below are the answers to some of our more frequently asked questions



#### Can any neonatal unit be involved in RePHyNe?

We are looking for Level 3 (Neonatal Intensive Care Units) and Level 2 (Local Neonatal Units) sites. Unfortunately, babies at Level 1 sites (Special Care Baby Units) won't meet the eligibility criteria.

#### Is there a minimum target number for recruitment?

No, we do not have a set minimum. Sites can set a low target with the aim of recruiting more participants. Every case contributes value and gives us more information about Neonatal PH.

#### Can sites without routine access to (advanced) echocardiography still participate?

Yes, while detailed echo data is encouraged where available, RePHyNe also incorporates clinical diagnostic inclusion criteria.