



Issue 1 | March 2023



Welcome to our first CSOR newsletter!

The National Perinatal Epidemiology Unit (NPEU) Parent Advisory Group (PAG) has now been running for a decade! Over that time you have helped to significantly improve the way we do research for children who need surgery.

The result of those ten years of work is the Children's Surgery Outcome Reporting programme (CSOR). Over the next decade, our ambition is that CSOR will make it possible for us to improve the things that the NPEU PAG have told us about.

These include it not being clear what the best treatments are for your children, and you receiving different advice on how to look after your child depending on who you talk to.

In these newsletters, we wanted to share with you results of the work you helped us with so far, explain some of the exciting things that are happening with CSOR, advertise ways you can get involved in CSOR, and highlight interesting new research for children who need surgery.

If you ever want to talk about anything in the newsletter, please get in touch

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Caring for a child with complex care needs at home, nursery and school

Finding out that your baby has a condition that will require neonatal surgery is a complicated experience. It can be a long journey filled with uncertainty and anxiety. In 2016 and 2017, Lisa Hinton travelled the country and talked to 44 parents about their experiences and issues such as diagnosis, birth planning, the surgery itself and life back at home. These interviews, which some of you took part in, helped to produce a [resource for parents and clinicians](#) published on Healthtalk.org to help them navigate these challenging times. She has also written three papers highlighting what could be done by clinicians to help make things better for parents of children who need an operation. You can read these papers [publications](#) on our website.



Over time, parents become expert carers of their child, and entire families learn to navigate a new landscape of needs, routines, and risks. By re-analysing these interviews, Lisa and her colleague Karolina have found that there are points on that journey that parents and families find particularly challenging. These include taking their child home after surgery, working out how to meet the complex needs of their child at home, and negotiating care for their child at nursery and school.

The CSOR team have recently been given funding to run a new study (see section below 'Get Involved: Understanding and improving care for a child with complex needs?') to understand how care during these transitions could be improved, or support offered in a more family-centred way, to make it easier for parents and families to negotiate some of these tricky times when caring for a child with complex needs.



Get involved...

What would you like to know about how successful treatments are in different hospitals?

One of the key things that you have told us is that the advice you receive about how best to treat your child differs depending on who you talk to. You have also told us that parents' experiences are very different depending on the hospital their child is treated in. As part of the CSOR programme we are building a website that parents can use to find out more about how many children are treated in different hospitals, what treatments hospitals offer for certain conditions, and importantly, what the health and wellbeing of children treated in different hospitals is like after treatment.

We would like your help to design that website and the information it presents. We will be designing the website over three meetings:

- Friday 19th May, 13:00-14:30, online
- Thursday 29th June, 10:30-15:30 at The Studio in Birmingham (Travel, food, accommodation and childcare can be provided).
- Friday 15th September, 13:00-14:30, online



If you are interested in helping, and think you might be able to attend the meetings, please email csor@npeu.ox.ac.uk

Understanding and improving care for a child with complex needs?

We are looking for parents of children, currently aged 4-8, who have neonatal surgery-related complex care needs and who were diagnosed with and had neonatal surgery for one of the following conditions:

- Gastroschisis
- Hirschsprung's Disease (HD)
- Congenital Diaphragmatic Hernia (CDH)
- Oesophageal Atresia/Tracheo-Oesophageal Fistula (OA/TOF)
- Necrotising Enterocolitis (NEC)
- Posterior Urethral Valves (PUV)

The study involves online interviews where we will ask you about your experiences of caring for your child at home, nursery and school. We will use this information to produce resources that can be used by clinicians and parents to try to make navigating caring for a child with complex needs easier. Click [here](#) to read more or email [Karolina](#) for details.

Spotlight on...

Congenital Diaphragmatic Hernia (CDH) and Anorectal Malformations (ARM)

Standardised guidelines to manage patients with CDH results in improved clinical outcomes

A study published in the last issue of the Journal of Pediatric Surgery found that the introduction of a standardised clinical practice guideline to manage children with CDH in a hospital in the US led to decreased extracorporeal membrane oxygenation (ECMO) use as well as improved clinical outcomes including survival to discharge. The paper concludes that “refinement of management strategies, implementation of new interventions, and meticulous care can improve outcomes in patients with CDH”.

Routine Anal Dilatations for Anorectal Malformations

A study published in the European Journal of Pediatric Surgery found that asking parents to routinely perform anal dilatations at home for children who had undergone an operation to treat their anorectal malformation did not lead to any reduction in the number of times children needed further operations. The paper concludes that “The use of routine postoperative dilatations does not significantly improve surgical outcomes following PSARP (an operation) in anorectal malformations”. This was a relatively small study though, and more information is needed before it can be said with certainty whether anal dilatations are beneficial or not.

Meet the team

CSOR is being run by a team of nearly 50 people across four universities and 10 hospitals. Each newsletter we'll introduce a few of those people so that you can get to know us all a bit better.

Marian Knight

Marian is a Professor of Maternal and Child Population Health at the University of Oxford. She initially trained in obstetrics and neonatal care, before becoming interested in trying to understand more about how to prevent people and populations from becoming ill. Marian's work focusses on trying to understand how to prevent rare and severe complications that occur during pregnancy, and the early life of a child. She is an international expert in preventing harm occurring to mother's during and after pregnancy, and in the latest honours list was awarded an MBE.



Simon Kenny

Simon is a consultant paediatric surgeon at Alder Hey Children's Hospital, as well as being the NHS's National Clinical Director for children and young people. Simon specialises in treating children with

Hirschsprung's disease (a condition where the nerves in the bowel don't work properly), and is a patron of the Hirschsprung's disease charity, CHAMPS appeal. Simon is passionate about trying to make sure that healthcare focusses on the needs of children and their families, and when he finally has some spare time, loves to sail.



Get in touch!

If you would like more information about CSOR, have a question about any of the issues raised here, or would like to suggest topics that we should cover in the upcoming issues of the newsletter, please contact the CSOR Project Team by email at csor@npeu.ox.ac.uk or by phone on **01865 617771**.

