



November 2017 Newsletter

# BAPS - CASS

British Association of Paediatric Surgeons Congenital Anomalies Surveillance System

The national system to study the surgical management of a range of neonatal conditions – enabling national audit in neonatal surgery

## NEC one-year outcomes published

Thanks to everyone who contributed to the NEC study, the results have just been published in Archives of Disease in Childhood, Fetal and Neonatal Edition. The study showed a one-year mortality rate of 29%. Being small for gestational age, and still receiving parenteral nutrition at 28 days after surgery were two key factors associated with an increased risk of one-year mortality. 60% of infants underwent at least one further operation in the first year after surgery, whilst 8% were still parenteral nutrition dependent one year after surgery. The full paper can be found at: <http://fn.bmj.com/content/fetalneonatal/early/2017/11/01/archdischild-2017-313113.full.pdf>

## Which outcomes should be measured in studies comparing treatments for Hirschsprung's disease?

Over the past two years, approximately 150 surgeons, paediatricians, people with Hirschsprung's disease, and parents of children with Hirschsprung's disease have worked to identify the outcomes that are most important in determining whether treatment of a child with Hirschsprung's disease has been successful or not. These outcomes are **mortality, quality of life, Paediatric Incontinence and Constipation Score, unplanned reoperation, long-term faecal incontinence, long-term voluntary bowel movements without need for enemas, or rectal/colonic irrigation, long-term urinary incontinence, need for a permanent stoma, long-term psychological stress for the individual with Hirschsprung's disease, and Hirschsprung's associated enterocolitis**, and they form the NETS1HD Core Outcome Set. The study has also been published in Archives of Disease in Childhood, and can be found at: <http://adc.bmj.com/content/early/2017/08/07/archdischild-2017-312901>

## NETS2HD study: Outcomes at six to seven years of age from a UK-wide cohort of children with Hirschsprung's disease

Thank you to everyone who has helped with setting up the NETS2HD study, which is now up and running in 22 of the 28 paediatric surgical centres in the UK and Ireland. Over 50 sets of parental contact details have been returned to the NPEU, and we have started collecting parent reported outcome data. We are hoping to have all contact details returned by the end of this year, so that we can aim to publish the results of the study by the beginning of 2019. More information about the study can be found at: [www.npeu.ox.ac.uk/nets/nets2/nets2hd](http://www.npeu.ox.ac.uk/nets/nets2/nets2hd), or you can email Benjamin.allin@npeu.ox.ac.uk

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Open the BARCODE READER APP\* on your phone and scan the code here

\*Search your app store for 'qrcode'



**Thanks to the following hospitals who have returned Surgical Short Bowel reports for July, August and September 2017:**

Addenbrooke's Hospital  
 Edinburgh Royal Hospital for Sick Children  
 King's College Hospital  
 Queen's Medical Centre  
 Royal Aberdeen Children's Hospital  
 Royal Belfast Hospital for Sick Children  
 Sheffield Children's Hospital  
 The Children's University Hospital  
 Alder Hey Children's Hospital  
 Bristol Royal Hospital for Children  
 Chelsea and Westminster Hospital  
 Great Ormond Street Hospital for Sick Children  
 Hull Royal Infirmary  
 John Radcliffe Hospital

Leicester Royal Infirmary  
 Norfolk and Norwich University Hospital  
 St George's Hospital  
 Royal Alexandra Children's Hospital  
 Royal London Hospital  
 Birmingham Children's Hospital  
 Evelina Children's Hospital  
 Glasgow Royal Hospital for Sick Children  
 Leeds General Infirmary  
 Our Lady's Hospital for Sick Children  
 Royal Manchester Children's Hospital  
 Royal Victoria Infirmary  
 Southampton General  
 University Hospital of Wales

Returned all three cards. Returned two cards. Returned one card. No Cards Returned.

**Case report summary for cases reported up until 13th November 2017**

CONDITION	Cases Reported	Forms returned (%)
Anorectal Malformations	212	172 (81%)
Duodenal Atresia and Stenosis	121	110 (91%)
Exomphalos	182	182 (100%)
Exomphalos 1yr Forms	152 requested	110 (72%)
Posterior Urethral Valves	165	136 (82%)
Posterior Urethral Valves 1yr Forms	122 requested	81 (66%)
Surgical Short Bowel	66	40 (61%)



*Chocolate Box*

Chocolates this month go to Cezar Nicoara from Alder Hey Hospital for picking up the reporting and for getting up to date with form returns.

**Many thanks from the BAPS-CASS team!**

**Do you have clinical questions you would like to answer using the BAPS-CASS datasets?**

BAPS-CASS datasets exist for congenital diaphragmatic hernia, gastroschisis, oesophageal atresia, exomphalos, anorectal malformation, short bowel syndrome, posterior urethral valves, necrotising enterocolitis and Hirschsprung's disease. Although these data were collected using resources from specific external grants, they are intended as a resource that can be used by all paediatric surgeons to answer questions that are of interest to them. Therefore, if you have a question that you would like to investigate using one of the BAPS-CASS datasets, they can be made available to you free of charge, all that is asked is that you first develop a scientifically robust proposal and submit this to the data guardian (Professor Jenny Kurinczuk) for review. This is the standard data sharing practice of the NPEU and safeguards the data for robust research. If you would like more information about using the BAPS-CASS datasets, please contact [baps-cass@npeu.ox.ac.uk](mailto:baps-cass@npeu.ox.ac.uk) or see the data sharing policies on the NPEU website.