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BPSU

BPSU Bulletin

The British Paediatric Surveillance Unit (BPSU) is part of the Research & Policy Division of the Royal College of Paediatrics and Child Health

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Inside this issue

Surveillance on Neonatal Exchange Blood Transfusions in infants of 28 days of age or under commences this autumn

This autumn sees the start of 13 month study on neonatal blood exchange transfusions (EBT). The study is to be led by Dr Ruth Gottstein (inset) of Manchester Children's Hospital is collaborating with the National Blood Transfusion Service.

Many babies develop a mild or moderate degree of physiological jaundice in the neonatal period, which if it requires treatment with phototherapy, usually responds to this and is harmless. Some babies, however, develop severe or rapidly increasing bilirubin levels e.g. in the presence of Haemolytic Disease of the Newborn or other pathologies. Bilirubin encephalopathy, which can result in cerebral palsy and / or deafness can ensue. It therefore necessitates prompt treatment with phototherapy but occasionally EBT is required.

The lead investigator Dr Gottstein stated that *"There is very little known about how often the procedure is performed currently in the UK & Ireland, or the complication rate. The collection of this information would be useful to inform medical practice and for counselling parents regarding consent for the procedure."*

The study aims to ascertain the current incidence and complication rates (including death) of EBT, as well as the practical difficulties of performing an EBT. There is insufficient understanding of the effect of current EBT procedures on the baby's clotting and platelet count, and therefore uncertainty about when the baby should have additional blood component support. Systematic collection of routinely available laboratory data will enable better recommendations for future practice and neonatal exchange red cell component development. A better understanding of the current incidence of adverse metabolic outcomes as a result of EBT, as well as incidence of morbidity and mortality, which will be invaluable to guide future practice.

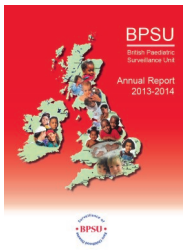
Clinicians will be asked to report "Any infant up to and including the age of 28 days undergoing an EBT during the past month". Funding for the study is coming from NHS Blood and Transplant Trustees Fund Grant & NICU Endowment Fund, St. Mary's Hospital, Manchester and has been approved by NRES Committee – North West – Greater Manchester Central (REC reference: 13/NW/0063; IRAS project ID: 115143) and has been granted Section 251 HRA-CAG permission (CAG Reference: 14/CAG/1010).

A lay public information guide is available at www.rcpch.ac.uk/bpsu/pil

For study protocol information go to www.rcpch.ac.uk/bpsu/ebt

Annual Report 2013-14 Published

The 29th annual BPSU report is now available on-line as a pdf at www.rcpch.ac.uk/bpsu/annualreports.



A limited number of hard copies are available, if you would wish to receive one please do let us know. The report contains the activities of the Unit over the year to June including an extensive report on the HIV study as well as reports on rubella; syphilis; PIND; Kawasaki disease; HUS; acute pancreatitis. The latter two have recently ended surveillance and we include an interim report on page 3 of this bulletin. We also highlight the success of the e-reporting which has led to an increase in the card compliance to 95%, a rise of nearly 2% on the year.

Supported by Public Health England, Royal College of Paediatrics and Child Health, and UCL-Institute of Child Health

Public Health England
RCPCH Royal College of Paediatrics and Child Health
UCL INSTITUTE OF CHILD HEALTH

BPSU Chair's Yearly Report

Dr Richard Reading

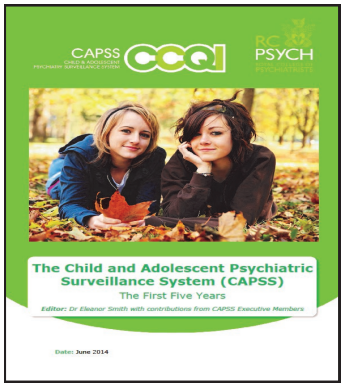
Dr Richard Reading (inset) writes "I became chair of the BPSU Scientific Committee in autumn of last year. It is a huge privilege and a daunting responsibility. Alan Emond led the BPSU through a testing time and left it a much stronger, more robust organisation when I took over.

Governance: There is a new governance structure for the BPSU, with an overseeing governance committee chaired by John Newton of Public Health England, with representation of the three parent bodies: Public Health England, RCPCH and UCL-Institute of Child Health. They are responsible for the strategic direction of the BPSU and ensuring the financial viability of the organisation. Our funding is still tight, in common with many other public bodies during these times, but a lot more secure in the longer term.

Dissemination: The work the BPSU continues apace with several more upcoming studies of public health and clinical importance in preparation which we are excited about. Our annual report is also now available at www.rcpch.ac.uk/bpsu/annualreports and it lists the 16 peer review publications produced in the past year from ongoing and completed studies and we continue to encourage investigators to disseminate their findings in high quality journals, conferences and in ways accessible to the public.

Public Engagement: One of these routes is through activities associated with the Rare Disease movement. Rare diseases are becoming important professionally, politically and commercially. The UK advocacy group is Rare Disease UK, and Richard Lynn, our scientific coordinator, sits on their management board as science advisor, has been very active in promoting the BPSU activities to this group. Richard organised a very successful Rare Disease day "tea party" earlier this year, hosted in the College and attended by children, families, advocacy groups, professionals and academics, and industry. We were delighted that Health Minister Earl Howe was able to attend and participate in the afternoon. A repeat party is planned for next March. The podcast on children's views of living with a rare condition produced and made by children can be viewed at www.rcpch.ac.uk/bpsu/rarediseaseday

Reporting: Most of you will have changed over to e-card reporting, and we are working to ensure as many as possible are able to complete orange card returns electronically. While some will regret the passing of the iconic orange post-card, e-card reporting has been associated with our highest ever response rate at 95%. Thanks to everyone for this. Our investigators depend on the "Nothing to Report" responses for reliable incidence measurement. We are a little concerned that questionnaire returns on reported cases are not so reliably completed. We try to ensure the information requested is reasonable and easily accessible in the notes. We are also piloting electronic data collection in some studies to see whether this helps, but please do return questionnaires as soon as possible on any cases you report.



CAPSS 5 Year Report

Studies: We encourage potential investigators to submit applications for new studies all the time. The BPSU is an internationally recognised surveillance system which continues to be spectacularly successful. There are changes in the research governance climate in the UK which may make some aspects of BPSU studies easier. For instance there is the opportunity for longer follow-up periods, the possibility of record linkage with appropriate safeguards, and the possibility of contributing to existing disease registers. Please contact Richard for more information. We are also working more closely with CAPSS (Child and Adolescent Psychiatry Surveillance System - who have recently published their five year report) on joint studies and protocols including ADHD transition.

We have been able to re-instate the Sir Peter Tizard Bursary for up-and-coming investigators. This year the bursary winner is Marie Wright from Edinburgh to undertake surveillance of the Pierre Robin Sequence.

BPSU Scientific Committee, September 2014

Committee news: I would like to record comings and goings on the scientific committee. Over the last year or so Mrs Ann Seymour, Mrs Sue Banton, Professor Simon Mitchell, Dr Colin Michie, Dr Piers Daubeney, Dr Delane Shingadia, Professor Carol Dezateux, Dr Sam Oddie, Dr Richard Pebody and Dr Ian Kennedy have all stepped down. Many thanks to all, some who had served the BPSU over many years. In their place we welcome Mrs Madeleine Wang, Dr Jane Sutton, Dr Kathryn Johnson, Professor Alastair Sutcliffe, Dr Marc Tebruegge, Dr Katie Russell, Dr Mohan Shenoy, Dr Rachael Wood. Professor Anne Greenough, Vice President - Science and Research in place of Professor Neena Modi.

Future: Finally, June 2015 marks the start of the thirtieth year of the BPSU. I hope the summary above reflects a vibrant and forward-looking organisation. While we will be celebrating the achievements over the past thirty years, our emphasis will be on the future. New technology, developments in public health, changes in public understanding and involvement in research all offer great opportunities. Emerging public health and clinical problems will continue to pose challenges the BPSU is ideally suited to responding to. With your support, the BPSU will thrive over the next thirty years as it has in the past thirty. Thanks to you all.

Contribution rate increase

Following the completion of the DH grant in 2012 the BPSU Governance Board undertook a financial review. In order to put the unit on a sustainable, along with the contributions from the researchers using the system, contributions from RCPCH; PHE; Health Protection Scotland and GOSH – Children's Charity and UCL have been promised for 2014-15. Following the financial review the contribution rates for running a study on the orange card reporting scheme will rise to £12,500 for a 13 month study and £6,500 for any additional 12 month periods of surveillance. This level will come in to effect on January 1st 2015 for all **NEW** applications received. The contribution rates for applications in progress will be held as long as these applications have reached the point of chair's approval by September 1st 2015. If these applications have not reached the point of chair's approval by September 1st 2015, these will be expected to contribute at the new rate.

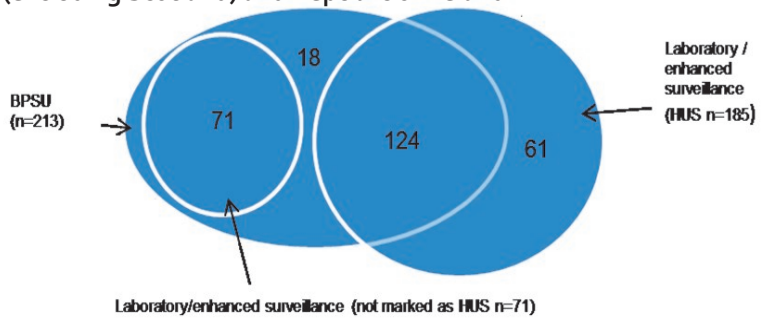
If you would like to discuss this rate increase please do get in contact with us at bpsu@rcpch.ac.uk.

Study News

Study completion: After three years the BPSU surveillance of **Haemolytic uraemic syndrome** ends in November. Please note that this condition is now a reportable disease to Public Health England. This study aims to measure the incidence of HUS in England, Northern Ireland, Wales and the Republic of Ireland, (Scottish data is being collected separately through Health Protection Scotland) and describe clinical and demographic features. By comparing the results from this study to that of the previous BPSU study any changes in epidemiology will be apparent. The one year follow-up will provide useful information on the outcomes of illness. By linking cases reported through this study to national surveillance systems for VTEC, we will seek to identify factors associated with an increased risk of developing HUS, in the hope that we might, in the future, be in a position to prevent at risk children from developing HUS following VTEC infection.

Over the 35 month period to August we have seen 543 cases reported of which 184 (34%) have so far been confirmed. We still have outstanding data on 128 (24%) reports and would urge all those who have yet to return their questionnaires to please do so. Reports are also being cross checked with the laboratories to make sure that we have maximised ascertainment.

Figure 1 Venn diagram of reported HUS cases across UK (excluding Scotland) and Republic of Ireland

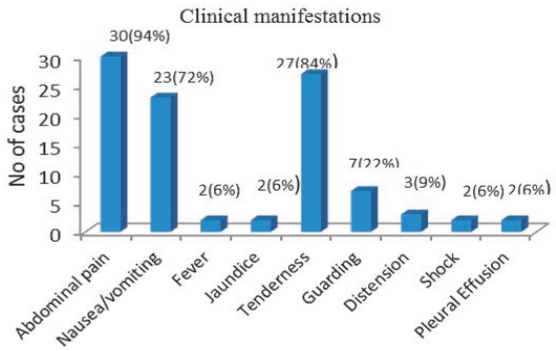


For the period 1st October 2011 - 31 December 2013; 61 cases have been identified as HUS through national surveillance systems of VTEC which are not captured through the BPSU study and study investigators are working to obtain questionnaires for these cases and improve ascertainment overall. (Figure 1)

In England, examination of laboratory data for HUS cases reported through the BPSU indicated that 13% of cases had no specimen submitted to Gastrointestinal Bacteria Reference Unit. 20 cases had specimens submitted but there was no evidence of VTEC infection. For further information: www.rcpch.ac.uk/bpsu/hus or email lisa.byrne@phe.gov.uk

Acute Pancreatitis: Surveillance for this condition ended after 13 months this June and the one year follow-up is now underway. The study aims to characterise the disease across the severity spectrum, the associated factors, such as obesity, and likelihood of death or long term complications. To date 221 cases have been reported; 105 have been confirmed 33 duplicates and 41 error reports with 42 (19%) for which data is still outstanding. Early data analysis shows the median age of diagnosis was 7.12 years, range (2.3 to 14.9 years). 69% were boys; the female to male ratio was 2:1.

Figure 2: Presenting clinical features for first 32 confirmed children with acute pancreatitis



Abdominal pain was the most common presenting symptom (94%), followed by nausea and vomiting (72%). Abdominal tenderness was the most common clinical sign (84%).

The interim analysis appears to confirm the original impression that although rare, acute pancreatitis is a condition that is seen in paediatric practice and has significant morbidity. Gallstones are now one of the commonest associations. Further analysis will reveal to what extent obesity may also contribute to this association.

For further information: www.rcpch.ac.uk/bpsu/apan or email a.a.majbar@bristol.ac.uk

Reports and Analysis

Recent publications: 1) IO Okike et al; the neoMen study group. Incidence, Aetiology and Outcome of Bacterial Meningitis in Infants Aged <90 days in the UK and Republic of Ireland: prospective, enhanced, national population-based surveillance Clin Infect Dis. 2014 Jul 4. http://www.ncbi.nlm.nih.gov/pubmed/24997051

2) R Reading et al. Gonorrhoea, chlamydia, syphilis and trichomonas in children under 13 years of age: national surveillance in the UK and Republic of Ireland. Arch Dis Child. 2014 Aug; 99(8):712-6.

3) S Adalat, T Dawson, SJ Hackett, et al. Toxic shock syndrome surveillance in UK children. Arch Dis Child 2014 May 1. http://www.ncbi.nlm.nih.gov/pubmed/24790135

4) C Haines et al Chylothorax development in infants and children in the UK. Arch Dis Child. 2014 Apr 4. http://www.ncbi.nlm.nih.gov/pubmed/24704707

5) E Basatemur and A Sutcliffe. Incidence of Hypocalcaemic Seizures Due to Vitamin D Deficiency in Children in the United Kingdom & Ireland. JCEM Ct 2014. Online. DOI: http://dx.doi.org/10.1210/jc.2014-2773

Analysis: The past year has seen the BPSU respondent compliance rate rise to an amazing 95% (Table 1). This the highest level for many years and reflects the success of the e-reporting system. We will now be rolling this out to all in the next 6 months. There have been some significant shifts in response rates over the last year with Mersey's response falling from their high response rates in 2012 of 95.6% to 92.9% for 2013. On the other end of the scale, Oxford's responses have improved significantly since 2012, jumping to 97.8% in 2013. Well done! However it is important to maintain the questionnaire response rate. This is currently at 87% some studies have of late struggled to get over 80% but and we need to raise this to over 90%. We are looking to secure on-line data collection and this is being trialled.

Table 1 - % Regional Response Rates Jan-Dec 2013

Region	Return %	Rank
Eangl	97.10%	5
Mersey	92.90%	19
NET	93.80%	18
NScot	97.20%	3
Nwest	94.80%	15
Northern	95.50%	10
Nire	93.90%	17
NWT	91.00%	20
Oxfrd	97.80%	1
Rire	94.70%	16
SET	95.20%	13
SScot	95.50%	9
Swest	95.10%	14
SWT	95.40%	12
Trent	97.10%	4
Wales	97.20%	2
Wessex	96.70%	6
WMids	95.40%	11
WScot	96.30%	8
Yorks	96.50%	7
Average	**95.30%**	

Table 2: All cases reported and follow ups to 17.09.2014

		VALID		INVALID			C&R	D&E	X
Condition	Start	C/R	D	E	X	TOTAL	(as % of total)		
HIV	1986	8,046	834	759	1,104	10,743	75	15	10
CR	1990	90	37	65	0	192	47	52	2
PIND	1997	2,108	459	1,068	72	3,707	57	41	2
SYP	2010	51	28	24	16	119	43	44	13
HUS	2011	184	138	93	128	543	34	43	24
PDA	2012	186	207	63	74	530	35	51	14
KAW	2013	302	51	78	221	652	46	20	34
APAN	2013	105	33	41	42	221	48	33	19
HEP	2014	38	2	9	20	69	55	16	29
GBS	2014	51	15	14	229	309	17	9	74
EPM	2014	12	0	6	117	135	9	4	87
Total		**11,047**	**1,804**	**2,220**	**2,023**	**17,085**	**65**	**24**	**12**

HIV	Human immunodeficiency virus in childhood
CR	Congenital rubella
PIND	Progressive intellectual & neurological deterioration
SYP	Congenital syphilis
HUS	Haemolytic uraemic syndrome
PDA	Surgical ligation of patent ductus arteriousus
KAW	Kawasaki Disease
APAN	Acute pancreatitis
HEP	Acute Symptomatic Hepatitis
GBS	Group B streptococcal disease
EPM	Enterovirus and parechovirus meningitis

C/R = confirmed/already known

D = duplicate

E = reporting error or revised diagnosis

X = status not yet reported to BPSU by investigator

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED