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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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BPSU seeks new committee members

Alan Emond

Alan Emond (inset) is standing down as the chair of the BPSU Scientific Committee from September 2013, and recruitment is open for a new Chair. We are looking for a research active paediatrician with experience in assessing proposals and chairing committees. A commitment to paediatric surveillance is essential and experience with a BPSU study is desirable. Simon Mitchell and Colin Michie have both come to the end of their second term on the committee, and our thanks to both of them for their contributions. The BPSU is seeking two new members of the Scientific Committee, who have experience in research and critical appraisal. A background in neonatology or general hospital paediatrics would be desirable, but applications are welcomed from any suitable candidates from paediatrics, public health or academic research.

Nomination details for the chair and members' positions is included in the April College newsletter pack, closing date for applications will be 19th May.

Finally our two lay members Sue Banton and Ann Seymour are stepping down from the Committee in September after 6 years in post. Their contribution to the Public Patient Involvement aspect of the BPSU has been invaluable. The task of finding replacements will commence soon and details can be found at www.rcpch.ac.uk/bpsu/news.

For further information on all the posts please contact Professor Alan Emond, BPSU Chair (allan.emond@bristol.ac.uk), or Richard Lynn, Scientific Coordinator (bpsu@rcpch.ac.uk).

For further information on the application process please contact: Joseph Callanan, Tel: 020 7092 6000 Email: joseph.callanan@rcpch.ac.uk.

BPSU Strategy Review

Following the confirmation that BPSU has funding until August 2015, it was considered opportune to undertake a review; looking strategically at the Unit's science and funding within a changing NHS. A meeting was convened in March of BPSU stakeholders and users including the Public Health England (PHE); UCL-ICH; RCPCH; specialty convenors; specialist commissioning and patient representatives. Six workshops were held covering topics such as expanding the BPSU research remit through one off and regional studies; working with Pharma; working with the new NHS; can BPSU address service delivery matters. On the funding side we examined the current contribution rates (there will be no change); working in partnerships commercial and academic; the PHE and Dept of Health. If you would like to find out more about the strategy review or would like to contribute your comments on how your BPSU should develop please do contact us at bpsu@rcpch.ac.uk.

Public Health England launched

April 1st 2013 saw the functions of the Health Protection Agency (HPA) transferred to Public Health England (PHE). Throughout the decades, HPA has maintained a strong interest in rare disease surveillance through the BPSU and has supported it as one of its three parenting bodies. PHE as HPA's successor will maintain the strong interest and support for BPSU. Whilst PHE will continue to input into the scientific review process, it is expected that there will also be a number of scientific applications to the orange card scheme from various departments in PHE. PHE is looking forward to continuing the fruitful decades-long collaboration that HPA enjoyed with BPSU.

'Surveillance' is defined as providing the right information at the right time and in the right place to inform decision-making and action-taking.

Read Towards a Public Health Surveillance Strategy in England
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127475/Towards-a-Public-Health-Surveillance-Strategy.pdf.

Supported by the Department of Health

Rare Disease Day 2013 – Rare disease without borders

February 28th 2013 marked the sixth international Rare Disease Day coordinated by EURORDIS and organised with rare disease national alliances in 24 European countries. On and around this day hundreds of patient organisations from more than 60 countries and regions worldwide are planning awareness-raising activities converging around the slogan "Rare Disorders without Borders." Activities took take place across Europe, all the way to Russia, continuing to China and Japan, in the US and Canada, and as far as Australia and New Zealand! Details are available at www.rarediseaseday.org.

Patients and their families who feel isolated because of the rareness of their diseases should know that there are more than 6000 rare diseases affecting more than 60 million people in Europe and the US alone. Most of these diseases are genetic, serious, chronic and debilitating. Despite the broad range of rare diseases, each with different symptoms and prognoses, patients with rare diseases generally face common problems. Reaching out across borders can help them find common solutions and remind them they are not alone.

Policies in healthcare and social services which have proven beneficial to people living with rare diseases in one country should be standardised and replicated internationally. This is the idea behind the European Union's call for countries to develop National Plans for Rare Diseases in all Member States by the end of 2013.This initiative is intended to improve coordination of rare disease policies at the national level – following a common road map – and then to harmonise them across Europe.

Thus the theme for 2013 reminds us tackling rare diseases with an international perspective is particularly important, in terms of research, health policy and for the millions of patients and families throughout the world who can break out of their isolation though a vast international network of solidarity.

Rare Disease Day in the UK was coordinated by Rare Disease UK. Receptions were held in London, Cardiff, Edinburgh and Dublin. At the Westminster reception RDUK's report investigating the value of care coordinators to both patients and the NHS was launched. This can be downloaded from www.raredisease.org.uk. Earl Howe also informed the audience that the UK rare disease programme currently under development would be ready for launch by the end of the year.

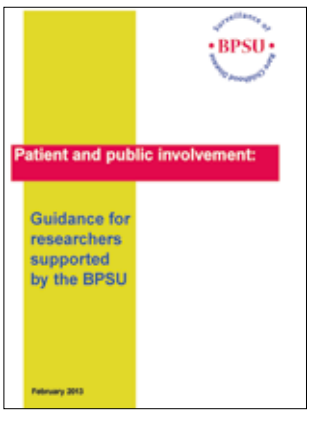
International Network of Paediatric Surveillance Units (INoPSU)

INoPSU continues to contribute to Rare Disease Day. INoPSU, which now has 13 countries involved in rare disease surveillance will be celebrating 15 years as a network at our 8th conference. This is to be held in conjunction with the International Paediatric Association conference in Melbourne Australia 24-29th August. The administrative work of INoPSU has now been passed to Australia who has coordinated the networks re-brand. The new logo has been launched and the website will be revised soon. Details on INOPSU studies undertaken in 2011/2012 can be found at: www.rcpch.ac.uk/system/files/protected/page/International%20studies%20list.pdf. If there is a study that is of interest and you wish to run through the BPSU please do get in touch.

EU Provides €144 Million for New Research on Rare Diseases: The European Commission (EU) will provide €144 million of new funding for 26 research projects, with the objective of delivering 200 new therapies for rare diseases by 2020. Read the press release at: http://campaigns.rarediseases.us/t/r-l-owhin-jdluklyuu-jy/.

BPSU launches Public Patient Involvement (PPI) guidance for researchers

As you are all aware the studies that the BPSU facilitate, unlike many research projects, do not approach patients or their parents. Our studies therefore are undertaken without consent and have to obtain approval from the National Information Governance Board to do so. PPI is important in research especially so when it does not involve individual consent, to ensure openness, transparency and accountability to the public. After an extensive review of the impact of PPI on its research activity, the BPSU has produced guidance for researchers on PPI in their research. This document has been designed to be an accessible and practical guide for those carrying out research through the BPSU, but we also hope it will be useful to a wider audience who are grappling with PPI in similar types of epidemiological surveillance. It offers practical advice on how to involve people, and provides examples of where PPI has been effective in BPSU studies. The guidance was developed by TwoCan Associates in collaboration with a steering group of BPSU Scientific Committee members, including its lay representatives. The BPSU is extremely grateful to the researchers, committee members and patient representatives who contributed to the guide.



To access the PPI guide and the results of the BPSU PPI evaluation, visit: www.rcpch.ac.uk/bpsu/ppi.

Route Maps for Rare Conditions Toolkit launched

Genetic Alliance UK have developed a Toolkit to support groups wishing to improve information provision as well as empower patients and their families to access better care and participate in decision making around their care.

The Toolkit has been designed to help with the creation of a condition specific Route Map to help patients and their families access the best possible care. It also enables health and social care professionals to provide their patients with the best possible care. The Toolkit is designed to help users create Route Maps for other users and so empower patients to plan their journey for treatment and care. This Toolkit is developed using the experiences of 10 pilot groups who created their own Route Maps. These were selected to ensure a wide range of rare conditions were covered, including: congenital (present at birth), adult onset, life-limiting and chronic. This was to ensure that a wide range of issues would be addressed. The experiences of patients and their families in the pilot groups showed that having a Route Map was beneficial to them. Because they were created using the experience of patients, the Route Maps gave participants the support and guidance they needed to enable them to participate in decision making about their care and to get the best possible care and treatment for their condition. For the pilot route maps, go to: www.geneticalliance.org.uk/routemaptoolkit.htm.

Study news

Surveillance of **acute pancreatitis** will now commence this April for a period of 13 months with a 12 month follow-up (principal investigator Professor Julian Hamilton-Shield, Bristol University Hospital). It was intended to commence in February however at the last minute we became aware of new consensus on the case definition being published. It was felt that we should follow the new consensus as it may in-validate any future potential papers.

NEW Surveillance case definition: Any infant or child up to the age of 15. Presence of at least two of the following three criteria. Imaging evidence is not necessary for diagnosis of acute pancreatitis if the other two criteria are fulfilled:

1) Clinical evidence (symptoms): Abdominal pain compatible with acute pancreatitis.

2) Biochemical evidence (laboratory):
   a) Serum amylase raised three times above the normal reference range for the local laboratory and/or
   b) Serum lipase raised three times above the normal reference range for the local laboratory

3) Imaging evidence (radiological): Signs of acute pancreatitis detected by changed in the imaging studies, like US, CT scan, MRI, MRCP etc.

Reporting instructions: Please report any newly arising cases of acute pancreatitis seen in a child less than 15 years in the past month fitting the surveillance case definition. Please report even if the case has now been referred to or from your paediatric/surgical colleagues.

Further information and references are available on the BPSU website at www.rcpch.ac.uk/bpsu/acute-pancreatitis or contact Professor Julian Hamilton-Shield. Email: j.p.h.shield@bristol.ac.uk or Dr Abdalmonem Majbar: A.A.Majbar@bristol.ac.uk.

Surveillance of congenital syphilis in children under 2 years of age: In January 2013, the BPSU Scientific Committee agreed to extend the active surveillance of congenital syphilis for a further two years. Since the re-emergence of infectious syphilis in the British Isles in the early 2000's, rates of diagnosis of infectious syphilis have increased amongst reproductive age women. Over the same period, cases of congenital syphilis were reported but no surveillance system was in place until the Health Protection Agency (now Public Health England), BPSU and UCL Institute of Child Health started active surveillance in 2010.

In the first 21 months of the study, more presumptive cases (12) of congenital syphilis seen than during the 36 month study conducted in the mid-1990s (n=9). The characteristics of the cases were also different. In the previous study cases were mainly seen amongst ethnic minority groups in London. Here, cases were seen in every English Strategic Health Authority (SHA) except South West, and Yorkshire and The Humber and were mainly of White ethnicity. The influence of the eastern European syphilis epidemic was also seen. Cases was generally seen in women who were unable to access healthcare services due to cultural barriers or chaotic lifestyles, and who experienced high levels of socio-economic deprivation. Consequently the mothers generally accessed clinical services in the third trimester, around the time of delivery.

The extension was granted for two reasons. Firstly, although a consistent pattern had emerged in the characteristics of cases, variability in the incidence of infection was higher than anticipated. The extension will allow us to investigate this variability in more detail. Secondly, the surveillance system used is the only methodology that can feasibly be used at present as the national surveillance systems lack the required coverage and sensitivity. Continuing the study for two years will allow time for a new national surveillance technique to be developed.

For further information contact Dr Ian Simms Email: ian.simms@phe.gov.uk.

Data collection and reporting

Recent publication: Neonatal Hypernatremia study has recently been published. Interest was such in the paper that is was widely reported in the press and the BBC.
The paper can be viewed at http://fn.bmj.com/content/early/2013/03/11/archdischild-2012-302908.full.

BPSU-card reporting: Clinicians in London have now been enrolled into the E-card reporting system which we are running through the RedCap consortium, bringing the total reporting electronically to 68%. We will be slowly rolling this out over the coming year taking care to monitor the response rate. At the current time this is 83% about 8% less than the postal card. An audit is underway to identify why this may be the case. Those wishing to receive the postal card can still so. An evaluation of the new system and your views on it will be undertaken in the summer.

What's in it for us – How reporting to the BPSU can help you: Clinicians wishing to revalidate will have to produce evidence at extended appraisals of commitment to professional standards and benchmarking of practice against peers. One useful piece of evidence will be a statement of participation in national surveillance studies, so the BPSU office is preparing to provide all reporting clinicians with an annual statement of their response rates, whether by orange card or e-card. We hope this will be a simple way of proving participation in important paediatric surveillance for the benefit of children's health.

If you report a case, you could also gain CPD points by writing reflective notes about the condition, how it presented to you, and what you learned from the research study. To complete this loop, BPSU will be encouraging researchers to send a pdf copy of the paper publishing results of their surveillance study by email to all those clinicians who reported cases.

Janet Masters 1952-2012: We are very sorry to announce the death of our dear colleague and friend, Janet Masters, on 18th December 2012. Janet was the Co-ordinator and Data Manager for the **National Study of HIV in Pregnancy and Childhood** at UCL Institute of Child Health. As some of our respondents will have known, she had been living with cancer for about 18 months. Although rarely the person who stood on the platform to present our findings, her dedication, attention to detail, and understanding of our work meant that others could do that with confidence. Janet was a great friend and advocate of the BPSU and we are really going to miss her. There is a tribute at www.ucl.ac.uk/nshpc/jmasters.

TABLE 1 - % response rate July-Dec 2012

Region	% rtnd	Rank
EAngl	96.3	2
Mersey	93.6	7
NET	88.5	19
NScot	94.9	3
NWest	91.3	10
North	94.1	6
NIre	90.6	14
NWT	89.0	18
Oxfrd	91.4	10
RIre	87.0	20
SET	91.4	10
SScot	91.9	9
SWest	94.3	5
SWT	90.2	15
Trent	90.1	16
Wales	90.9	13
Wessx	97.1	1
WMids	92.7	8
WScot	89.3	17
Yorks	94.6	4
Average	**91.8**	

DATA IS PROVISIONAL AND SUBJECT TO CHANGE

TABLE 2: All cases reported and follow ups to 02.04.2013

		VALID				INVALID		C&R	D&E	X
Condition	Start	C	R	D	E	X	TOTAL	(as % of total)		
AIDS/HIV	1986	7,194	113	782	712	1,185	9,986	73	15	12
CR	1990	73	12	35	30	11	161	53	40	7
PIND	1997	1,879	0	414	895	182	3,370	56	39	5
Lead	2010	22	0	3	10	23	58	38	22	40
SYP	2010	53	0	9	9	23	94	56	19	24
VITD	2011	42	0	4	18	49	113	37	19	43
HUS	2011	87	0	63	31	71	252	35	37	28
GID	2011	10	0	2	40	70	122	8	34	57
PDA	2012	0	0	2	2	222	226	0	2	98
KD	2013	0	0	0	4	71	75	0	5	95
Total		**9,360**	**125**	**1,314**	**1,751**	**1,907**	**14,457**	**66**	**21**	**13**

AIDS/HIV ... Human immunodeficiency virus in childhood
CR ..... Congenital rubella
PIND ..... Progressive intellectual & neurological deterioration
Lead..... Raised Blood Lead Levels in Children
SYP ..... Congenital syphilis
VITD ..... Seizures Vitamin D Deficiency
HUS ..... Haemolytic uraemic syndrome
GID ..... Gender identity disorder. Excludes psychiatry reports
PDA ..... Surgical ligation of patent ductus arteriousus
KD..... Kawasaki Disease

C confirmed/ already known

D duplicate

E reporting error or revised diagnosis

X status not yet reported to BPSU by investigator