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BPSU Bulletin

Dr Richard Reading - new Chair of the BPSU

We have the pleasure of announcing that Richard Reading has re-joined the BPSU as chair. He has taken over the position from the outgoing Chair Professor Alan Emond.

Richard is a consultant community paediatrician at Norfolk and Norwich Hospital. He has vast experience of working in the field of disease epidemiology and he was a BPSU committee member for seven years to 2012. Richard is well versed in the BPSU ways of working having undertaken several BPSU facilitated studies. He was co-investigator on the conversion disorder study and lead investigator in two studies - the genital herpes and sexually transmitted infections in children under thirteen years of age presenting to secondary care.

Richard has also sat on the child and adolescent psychiatry surveillance system scientific committee as a paediatric representative.

Richard states "*BPSU has successfully come through several turbulent years under skilled hands. I am immensely grateful to Alan Emond, the outgoing chair for steering the BPSU and leaving it in such a strong position. I hope to build on Alan's work and continue the implementation of newer methods of working, including the use of electronic systems, and expansion of public involvement in BPSU working. What must not change is the integrity of robust surveillance methods. This is what underlies the high esteem the BPSU is held in across the world, and I hope to maintain and strengthen this reputation.*"

UK rare disease strategy launched

This November saw the UK rare disease strategic plan launched by Lord Howe. The plan was produced as a response to an EU Commissions requirement that nation states submit a rare disease plan by end of 2013. The plan has been drawn up with considerable input from those involved in rare disease including the BPSU.

The strategic vision of the plan is to promote equity of access; offer a patient centred, coordinated approach to treatment services; deliver a holistic approach to diagnosis and treatment of rare diseases; promote collaborative work; education and training and to promote the UK as a first choice location for research into rare diseases. The plan can be viewed at www.gov.uk/government/publications/rare-diseases-strategy

In advance of the plan Rare disease UK released their report on Centre's of Excellence. It reiterated the view in the strategy plan on the functionality of such centres e.g. should offer coordinated care; have arrangements for transition to adults' services and be research active. RDUK also proposed that such centres offer education and training for medical professionals and where existing be members of international networks of excellence. For the RDUK report go to www.raredisease.org.uk/documents-to-download.htm

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Public Health England

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BPSU

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

Editor
Richard Lynn
BPSU Scientific Coordinator

Tel: 020 7092 6173
Fax: 020 7092 6001
Email: bpsu@rcpch.ac.uk
Website: www.rcpch.ac.uk/bpsu

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Study News - raised blood levels in children

Public health interventions have succeeded in removing most sources of lead from the environment. However, a small proportion of children continue to be exposed to harmful levels of lead, usually in the home. Exposure to lead in children is associated with a range of adverse health effects, from sub-clinical neurodevelopmental impairment to encephalitis.

Dr Ruth Ruggles

There is no reliable data on the incidence or prevalence of clinically significant lead toxicity or the prevalence of elevated blood lead concentrations in children in the UK. Currently, the UK has no formal monitoring for blood lead concentrations within laboratories of clinical systems. The aim of this study was to provide an estimate of the incidence of elevated blood lead concentrations in children. The study provided important information on the management of cases, both clinically and in terms of public health response.

- In total, 180 reports of lead poisoning have been received, with the laboratories being the highest volume reporter`

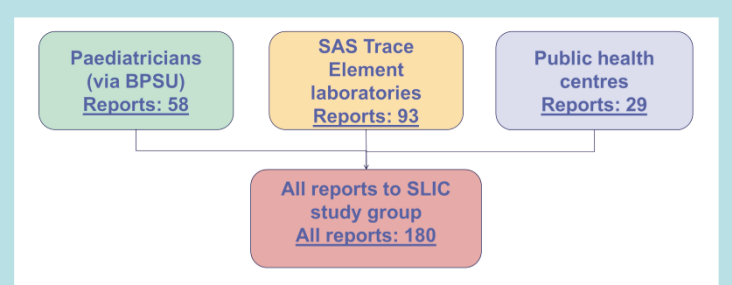


Figure 1: Reports received from each notification stream. These are still being investigated to ensure they meet the case definition and to remove duplicates.

- 35 cases of clinically diagnosed lead poisoning have been confirmed in children via the BPSU and Supra Regional Assay Service (SAS) laboratories; these are interim results and more cases are likely to be identified as later reports are followed up
- 93 notifications were reported by the SAS Trace Elements Laboratories. 21 of the 93 were linked to BPSU notifications.
- Of the remaining 72, 4 have been confirmed, 34 are being followed up and 34 have been excluded.
- Lead paint has been confirmed as the exposure source in most cases

Data is interim and whilst the numbers of cases reported to the study are small, this is an improvement on existing surveillance systems which rely on ad hoc reporting to public health agencies, such as Public Health England.[1]

Training impact: A webpage for the project is maintained within the Public Health England website at www.hpa.org.uk/chemicals/slic. A set of frequently asked questions (FAQs) for paediatricians and other clinicians was developed in response to requests for more information about the diagnosis, investigation and management of cases. These and FAQs for members of the public are available on web site (www.hpa.org.uk/chemicals/lead). Training events for health professionals have been organised in England. Participants have included Environmental Health Officers and Public Health England staff working in local and regional teams.

Conclusions: This is the first time that both paediatricians via the BPSU and non-infectious laboratories have been used as a reporting source for environmental public health surveillance. Laboratories have proved to be a valuable resource for lead poisoning data and this collaboration will be sustained after study is complete. We will use this information to develop a methodology for the routine reporting of other potentially environmentally related diseases, and tools for hypothesis generation and the relationship between environmental hazards and health. Lead poisoning is preventable and should be a primary public health objective. Initiatives seeking greater national and international collaboration will help us to better understand and address the health challenges that lead presents.

1. S Brailsford, R Kamanyire, R Ruggles. Lead poisoning cases associated with environmental sources. *Chemical Hazards and Poisons Report*. January 2008 Issue 11

www.hpa.org.uk/Publications/ChemicalsPoisons/ChemicalHazardsAndPoisonsReports/

For further information about the study, please contact:

Dr Ruth Ruggles, Email: Ruth.ruggles@phe.gov.uk

Study News - Acute Symptomatic Infectious Hepatitis

In January 2014, the BPSU will launch a new surveillance study on acute symptomatic infectious hepatitis for a period of 13 months with a 12-month follow-up period. The study is led by Dr Shamez Ladhani at Public Health England in collaboration with St. George's University of London.

Dr Shamez Ladhani

Hepatitis remains a key public health priority in most industrialised countries, yet little is known about the epidemiology, causative agents, clinical features, risk factors, management or outcome of children diagnosed with acute infectious hepatitis. Acute hepatitis is characterised by an acute onset of discrete symptoms including fever, jaundice, abdominal pain, nausea and vomiting. Occasionally, the condition may progress to fulminant hepatic failure and the need for liver transplantation. Most childhood cases of acute hepatitis are infection-related, with Hepatitis A (HAV) and B (HBV) being the commonest causes. Although effective vaccination against both HAV and HBV are available, they are not routinely used in the UK because these infections are considered to be rare.

As per the definition below, clinicians who look after children aged one month up to 14 years with raised levels of the liver enzyme, alanine transaminase (ALT) with or without jaundice and any suspicion of an infective cause (with or without an identified causative agent) should report the case through the BPSU orange card.

The BPSU surveillance methodology provides a unique opportunity to collect vital clinical and epidemiological information on hospitalised cases of acute symptomatic infectious hepatitis, irrespective of the causative agent(s). In the past, this has not been possible because national surveillance systems are not set up to reliably identify all acute hepatitis cases. The BPSU study will not only allow assessment of the contribution of vaccine-preventable causes in context with the total burden of disease, but provide invaluable data on other potential causes of acute infectious hepatitis and enable comparison of disease characteristics cause by different pathogens. Collection of clinical data through the BPSU would also help determine where and how children with acute hepatitis are investigated and managed and identify factors that contribute to referral of cases to intensive care and/or tertiary hepatology centres. Understanding the contribution of different agents causing acute infectious hepatitis in childhood and possible risk factors will be important for informing the investigation, prevention and management of this condition.

Case Definition: An acute hepatitis in any infant or child aged **1 month up to 14 years** of age with:

- **discrete onset of symptoms** (e.g. fever, jaundice, abdominal pain, fatigue, loss of appetite, nausea or vomiting); AND
- **elevated serum alanine aminotransferase** (ALT) levels (>2 x upper limit of normal); AND
- **not due to drug-induced, metabolic or auto-immune hepatitis**

Funding: This study is funded by an unrestricted, investigator-initiated grant from GlaxoSmithKline (GSK) Biologicals who have no involvement in running the study and is taking place in collaboration with St. George's University of London

Ethics approval: This study has been approved by NRES Committee East of England - Cambridge Central (REC reference: 13/EE/0392; IRAS project ID: 114805)

For further information about the study, please contact:

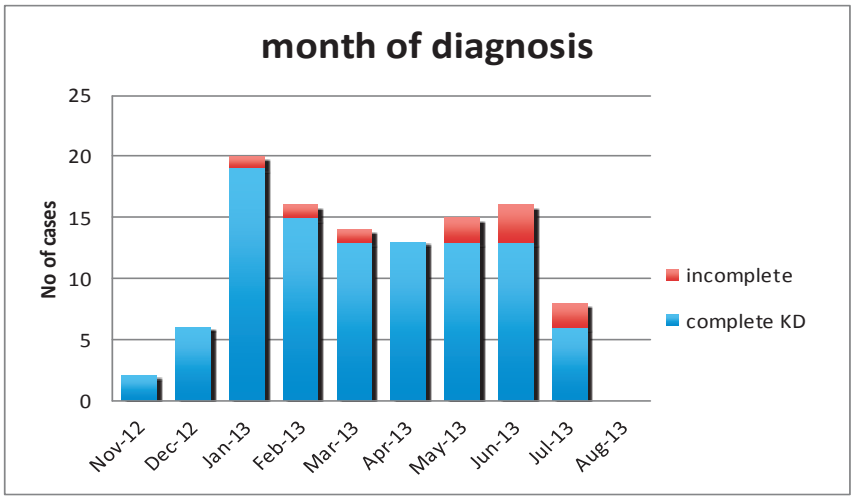
Dr Shamez Ladhani, Immunisation, Hepatitis and Blood Safety Department, Public Health England, 61 Colindale Avenue, London NW9 5EQ, United Kingdom.

E-mail: shamez.ladhani@phe.gov.uk

In the news

New studies: Several new studies are due to commence in the next few months. The Tizard bursary winner of 2011 Mary Salama is currently awaiting final ethics approval for her study on acute rheumatic fever. Ruth Gottstein's study on exchange blood transfusion will start in the New Year. The BPSU has also approved a second study on Group B Streptococcal disease, principal investigator Paul Heath and this has now been submitted for ethics approval.

Extensions: Kawasaki disease (KD) surveillance will continue for a further year until February 2015. 279 case reports have been received but there have been many case reports with fewer clinical criteria in addition to fever, and where cardiac involvement has been described (Figure 2). Here the clinicians are of the opinion that the case is KD and have treated as such. Because of the strict surveillance definition applied with the survey, it has not been able to include/collect the data on these cases.



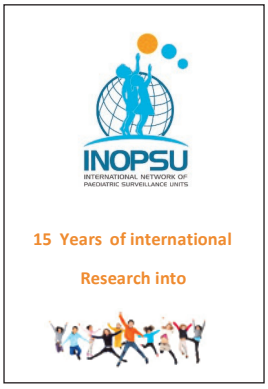
IMPORTANTLY: With approval from BPSU and REC the surveillance case definition has been widened to include incomplete or atypical cases. In addition, the current feeling of those in the research team is that the presence of streptococcal infection **does not** rule out KD and this should not be used as an exclusion criterion.

PLEASE REPORT: Any infant or child up to the age of 16 years presenting for the first time **with Fever of 5 or more days duration *plus* 4 of the following;** OR Fever ***plus*** **any two of the following and/or coronary artery changes**:

1. Conjunctivitis	Bilateral, bulbar, non-suppurative
2. Lymphadenopathy	Cervical > 1.5cm
3. Rash	Widespread, polymorphous. *Not* vesicular.
4. Lips and mucosa	Red cracked lips, 'strawberry tongue', erythematous oral cavity
5. Changes of extremities	Erythema, oedema of palms and soles initially, then peeling of skin at later stage.

Reports and analysis

International activities: The International Network of Paediatric Surveillance Units (INOPSU) celebrated its 15th anniversary with a symposium as part of the recent International Paediatric Association conference in Melbourne.



Entitled "The Power of International Collaboration to Study Rare Diseases" the symposium was well attended by INoPSU representative paediatric delegates from around the world. There were three sessions to showcase the achievements of INOPSU over the last 15 years including the impacts of INOPSU results on clinical practice and policy. Examples include: changes in legislation for child restraints and seatbelts to keep young children safe from injury; supporting vaccination programmes including polio, rubella, and varicella; supporting a review of diagnostic criteria for early onset eating disorders and fetal alcohol syndrome; the value of long term surveillance for very rare groups of conditions such as progressive intellectual and neurological deterioration in children.

The meeting concluded with at the launch of the new INoPSU website and a report on the first 15 years of INoPSU (www.inopsu.com).

Data collection and reporting

BPSU annual report: The latest BPSU Annual Report has now been published and can be accessed via the website www.rcpch.ac.uk/bpsu/annualreports . For those who wish a hard copy we do have a few available on request. The report includes details on current studies such as HIV, rubella, PIND and gender identity disorder.

BPSU and revalidation: The BPSU is now in a position to send individualised details of your orange card responses. In the summer we sent an email to you with your personalised response details and this can be used as evidence for revalidation. We hope to extend this soon by sending out where appropriate your case reporting details; as well as your monthly reporting details; so do look out for this.

E-reporting: We now have over 2500 (75%) respondents reporting via our E-web service. Of these we receive 1500 (70%) within a week. But we have to send out weekly reminders to get the response up to 90%. For those who wish to change to e-card reporting there is now a box on the postal card which you can tick and we will switch you ASAP or you can contact the office bpsu@rcpch.ac.uk . Though e-reporting is working we are still having some problems in certain areas, in particular Wales where we are trying to find a solution. Those individuals not responding for 3 months to e-card reminders will be reverted back to the postal card until we hear otherwise.

Table 1 - % Regional Response Rates

Region	Return %	Rank 2013
Eangl	96.50%	1
Mersey	93.60%	13
NET	89.20%	19
NScot	96.20%	3
Nwest	93.10%	10
Northern Ireland	94.30%	9
Nire	93.40%	14
NWT	87.20%	20
Oxfrd	95.90%	4
Rire	93.70%	12
SET	89.70%	10
SScot	94.20%	10
Swest	95.80%	5
SWT	91.80%	16
Trent	94.90%	7
Wales	90.60%	17
Wessex	96.30%	2
WMids	94.30%	8
WScot	93.80%	11
Yorks	95.70%	6
Average	**93.10%**	

DATA IS PROVISIONAL AND SUBJECT TO CHANGE

TABLE 2: All cases reported and follow ups to 02.11.2013

		VALID			INVALID		C&R	D&E	X
Condition	Start	C	D	E	X	TOTAL	(as % of total)		
AIDS/HIV	1986	7,722	800	729	1,026	10277	75	15	10
CR	1990	89	37	62	3	191	47	52	2
PIND	1997	2018	426	1017	41	3502	58	41	1
VITD	2011	42	4	18	74	138	30	16	54
HUS	2011	111	91	56	113	371	30	40	30
GID	2011	20	1	78	39	138	0	200	28
PDA	2012	131	14	38	217	400	1	18	54
KAW	2013	102	14	40	120	276	2	33	43
APAN	2013	19	3	41	39	102	3	105	38
Total		**10254**	**1390**	**2079**	**1672**	**15395**	**67**	**23**	**11**

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
APAN Acute pancreatitis
KAW Kawasaki Disease

C = confirmed/already known

D = duplicate

E = reporting error or revised diagnosis

X = status not yet reported to BPSU by investigator