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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

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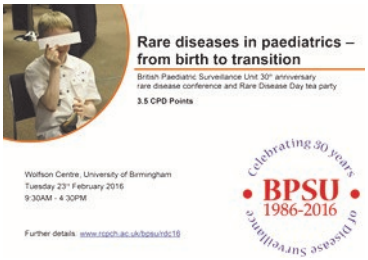
BPSU Bulletin

The BPSU celebrates 30 years of surveillance

To celebrate the 30th anniversary of the BPSU facilitating research into rare paediatric conditions a conference will be held at the University of Birmingham on 23rd February 2016.



The conference theme is Rare disease in Paediatrics from birth to transition and will centre on the patients journey from diagnosis through transition and to end of life care. Sessions will cover improving and speeding-up diagnosis; research in practice; and adolescence and beyond.

Cutting edge scientific data will be presented by the likes of Professor Bobby Gaspar, (GOSH), Professor Richard Pebody (PHE), Dr Martin Ward-Platt (RVI). The Chief Knowledge Officer, John Newton will oversee the activities.

Full programme details can be found at www.rcpch.ac.uk/bpsu/rdc16 along with details on how to register.

There will be also be an exhibition area with commercial and charity stands. On the day we will also take the opportunity to recognise Rare Disease Day with our tea party.

Surveillance of visual impairment & blindness

A study on severe visual impairment and blindness in children/young people aged 18 years or under commences in October and will run for 13 months with a 12 month follow-up. The study is led by Professor Jugnoo Rahi, Professor of Ophthalmic Epidemiology and Honorary Consultant Ophthalmologist at UCL-Institute of Child Health. This is the second time this condition has been surveyed by the BPSU and, as in the 2000 study, surveillance will undertaken in conjunction with the British Ophthalmological Surveillance Unit.


Professor Jugnoo Rahi

Clinicians are asked to report any cases of children/young people ≤18 years in the past month newly diagnosed as severely visually impaired or blind in the UK (Republic of Ireland excluded) as defined as any child / young person:

- with corrected distance acuity worse than 6/60 Snellen or LogMAR 1.0 in the better eye **OR**
- is eligible for certification to the national registers of sight impairment **OR**
- with clinical features consistent with SVI/BL **OR**
- assessed as having special educational needs due to SVI/BL.

Professor Rahi stated "*It is hoped that the findings from this study will inform planning of prevention and treatment strategies and targeting of screening; 'map' clinical and public health services involved in detection and management thereby informing the commissioning and delivery of NHS services; and present an evidence base on the sociodemographic variations in childhood visual disability to inform national public health policies.*"

The study is funded by Fight for Sight. This study has been approved by NRES Committee – London – Bloomsbury (REC reference: 14/LO/1809; IRAS project ID: 161997) and has been granted Section 251 HRA-CAG permission (CAG Reference: 14/CAG/1028).

The study protocol information and a lay public information guide which can be distributed in your ward/clinics is available form is available www.rcpch.ac.uk/bpsu/BCVIS2.

For further information, please contact: Lucie Teoh; research associate - l.teoh@ucl.ac.uk.

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

Studies to commence

Several studies are due to commence over the next few months and they are described, below.

Professor Tamsin Ford

Children and adolescents with ADHD in transition between children's adult services (CATCH-US)

This study commences in November and will run for 7 months in the first instance with a 9 month follow-up. The study is led by Professor Tamsin Ford, Exeter University (inset).

Paediatricians and Psychiatrists are asked to report any existing cases that you see of a young person with ADHD taking medication for ADHD who is **reviewed by you for the first time in the six months preceding the young person reaching your service's age boundary**. Also please report any case, even if you believe the case may have been reported from elsewhere.

Professor Ford stated "*This study aims to estimate the range and mean age for transition to adult services and variation within this across the UK and Republic of Ireland for CAMHS; to estimate the incidence rate of young people with ADHD who require ongoing medication for ADHD after they pass the age-boundary for the service that they attend and variation within this across the UK and Republic of Ireland; to describe what services are offered to young people going through this age-boundary; to estimate the proportion of young people with ADHD judged in need of transition who successfully transfer to a specialist adult health service, defined as an accepted referral to adult services within the time frame of the current study.*

Our objective is to provide recommendations to improve service delivery and provision for young people with ADHD and thus improve their health at a key life stage and beyond."

The study is funded NIHR HS&DR Themed Call: Long-term conditions in children and young people. This study has been approved by NRES Committee – Yorkshire & Humber – South Yorkshire Research Ethics Committee (REC reference: 15/YH/0426) and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0184).

The study protocol information and a lay public information guide which can be distributed in your ward/clinics is available form is available www.rcpch.ac.uk/bpsu/ADHD

For further information, please contact; Professor Tamsin Ford: t.j.ford@exeter.ac.uk

Dr Deborah Hodes

Female Genital Mutilation (FGM). will also start In November and will run for 13 months with a 12 month follow-up. The study is led by Dr Deborah Hodes from University College Hospital, London and is being undertaken in conjunction with the RCPCH Research and Policy Division.

It is estimated that 125 million women across the world today have had some form of FGM. No one really knows how common FGM is in the UK and ROI, but there are some estimates that over 100,000 women in the UK have had FGM. At the moment it is rare for doctors or any other professionals working with children to see FGM. This might mean that it only happens rarely; but it could also be because professionals are not asking about FGM or do not recognise the signs.

This study will help us find out how often doctors are referred children with suspected or actual FGM – this will help to plan health services in light of better knowledge about how common it is, rather than working with the current estimates of the large numbers of children thought to be at risk. It will also examine why children with suspected or actual FGM are being seen - who referred to the paediatrician and why – this will help us to educate professionals working with children about the presenting features and develop guidelines. It may also give us some information about children with FGM who are more likely to be missed, and how to prevent this. Clinical data will be collected electronically to maximise confidentiality.

The Health and Social Care Information Centre (HSCIC) have already started collecting data about doctors seeing FGM. We are planning to work with the HSCIC to try to avoid missing cases of FGM. We are also planning to send the electronic card to paediatric surgeons (as well as paediatric doctors) because we think that they might see some cases of FGM. The Sexual Assault Referral Centres (SARCs) in the four nations have agreed to participate.

Please report a new presentation of any child aged under 16 (i.e. up to 15 years 11 months) last month, not already known by you to have FGM who was

- Seen because of suspected FGM (for example referrals from social care)

OR

- Seen for another condition and FGM is suspected following assessment **OR**
- Has a genital piercing **OR**
- Has had female cosmetic genital surgery including labioplasty.

If uncertain or awaiting further assessment, please refer the child.

Funded by the Department Of Health and has been granted Section 251 HRA-CAG permission (CAG Reference: 15/CAG/0178).

PLEASE NOTE THE REPORTING TO BPSU DOES NOT OBLIGATE THE CLINICIANS RESPONSIBILITY FOR REPORTING OF CASES TO THE APPROPRIATE AUTHORITIES

The study protocol information and a lay public information guide which can be distributed in your ward/clinics is available form is available www.rcpch.ac.uk/bpsu/FGM

For further information, please contact: Dr Najette O'Connell, Clinical lead n.ayadio'donnell@nhs.net

Study update

Professor Mitch Blair

Rickets surveillance –the need to maximise ascertainment—The Nutritional Rickets Presenting to Secondary Care study aims to review the incidence and clinical management of rickets in the UK and Republic of Ireland in children aged 0-16 years. The study is being led by Dr Priscilla Jules from Royal Free in conjunction with the RCPCH Research and Policy division. The project went live on the 1st March 2015 and unlike the traditional method of paper based BPSU data collection methodology, this project is the first to use an online clinical questionnaire and reporting system.

Though we have received an average of 15 cases a month for the past 6 months, a good response, the number of case reports was expected to be higher. This may be due to an extreme seasonal effect and more cases may be reported as we move towards the winter. But there is concern that under ascertainment may be occurring.

In the first six months we have received 83 case reports of which 30 (36%) have so far have been confirmed, 50 (60%) have been reporting errors and data on 3 (4%) is still awaited. Of the confirmed cases, 29 (96%) are under the age of 5. Ethnic breakdown is as follows - African/Caribbean (n=14), Pakistani (n=8), Indian/Bangladeshi (n=4), Any other white background (n=2), Other mixed (n=2).

Please do report any cases of children 0-16 years arising since March 1st presenting with either clinical or radiological rickets as defined by the case definition.

The case definition is **Clinical Rickets** with any of the following:

Leg deformity (bowing or knock-knees)/Swollen wrists or knees or ankles or ribs (Rachitic Rosary) **AND** 25OHVitamin D <25nmol/L with one or more abnormalities of serum calcium, alkaline phosphatase, phosphate, parathyroid hormone.

OR

Radiological Rickets with widening, cupping, splaying of metaphysis (of any long bone) **AND** 25OHVitamin D <25nmol/L

Exclusion Criteria:

- Vitamin D dependent rickets e.g. 1α-hydroxylase deficiency - vitamin D resistant rickets e.g. familial or X-linked hypophosphataemic rickets.
- Rickets associated with other chronic diseases e.g. malabsorption, liver disease, chronic renal disease
- Metabolic bone disease of prematurity (infants whose corrected age is < 3 months at presentation, who were born < 36 weeks gestation and weighing <1.5kg

The study protocol information and a lay public information guide which can be distributed in your ward/clinics is available from www.rcpch.ac.uk/bpsu/RKT

For further information, please contact: karina.pall@rcpch.ac.uk

Type 2 diabetes - This study commenced in April 2015 for 13 months with a one year follow-up. The study is led by Professor Julian Hamilton Shield (inset) of Bristol University Hospital. The study is his 2nd BPSU study will ascertain whether the incidence of Type 2 diabetes has increased since the first survey ten years ago, and will re-assess diagnosis and management of this condition in the UK.

In the 2004 BPSU study, funded by Diabetes UK, we identified 78 new cases (incidence cases) in a year and childhood obesity appeared to be a major association. Since 2004, levels of childhood obesity have continued to increase and we suspect cases of Type 2 diabetes will also be increasing in parallel.

To date we have received 60 notifications of which we have had 31(51%) replies; 15 (25%) have been confirmed and 13 (22%) are under review, the rest are outside the reporting period. We need to improve the questionnaire response so will be re-contacting those reporting a case in order to try and collect the outstanding data or sort out any issues that make exist.

Please do continue to report, given the rarity of this condition, every case is particularly important

The study protocol information and a lay public information guide which can be distributed in your ward/clinics is available form is available www.rcpch.ac.uk/bpsu/T2D

For further information, please contact: Toby Candler: tc15585@bristol.ac.uk

In general

BPSU activities through the coming year – As part of the BPSU 30th year activities the BPSU will be hosting a short session at the Excellence in Paediatrics conference in London on 10th December. So do look out for the team if you are attending.

Also, the BPSU will be holding an afternoon session at the RCPCH scientific meeting in Liverpool on the Wednesday 27th April. The aim is to demonstrate the BPSU's current and future impact in the field of child public health. Details available from bpsu@rcpch.ac.uk

The BPSU latest annual scientific report is now ready to download and can be accessed at www.rcpch.ac.uk/bpsu/annualreports. The report contains information on current studies include study updates from the neonatal exchange blood transfusion, HIV and Kawasaki disease teams, as well as the most recent publications from completed studies.

LinkedIn – BPSU now exists as a group on LinkedIn – so do join as we will be using it as a platform to update members on BPSU activities. BPSU also has a Twitter account . This will likely be the last bulletin in this format – thereafter we will be producing an e-newsletter with shorter articles hyperlinked to our webpages. Please do give us feedback on all our activites.

Reports and Analysis

Analysis: For the period December 2014 to May 2015 orange card return rates stand at 92.6% (Table 1). There have been some significant shifts in response rates over the last year with South West's response rate falling from their high response rates in 2014 of 94.9% to 91.1% for 2015. On the other end of the scale, East Anglia's responses have improved significantly since 2013, jumping to 96.6% in 2015 and is regionally the second best returner of orange reporting cards.

However, it is important to maintain the questionnaire response rate. This currently stands at 86%, but some studies have, of late struggled to get over 80% and we need to raise this to over 90%. questionnaire.

Table 1 - % Regional Response Rates December 2014 –May 2015

Region	% retd	rank
EAngl	96.6%	2
Mersey	94.1%	6
NET	90.3%	19
NScot	98.3%	1
NWest	91.4%	13
North	90.7%	18
NIre	91.3%	16
NWT	91.4%	14
Oxfrd	93.3%	8
RIre	89.2%	20
SET	93.0%	9
SScot	92.4%	12
SWest	91.1%	17
SWT	92.6%	10
Trent	91.4%	15
Wales	94.9%	5
Wessx	95.5%	4
WMids	92.6%	11
WScot	95.8%	3
Yorks	93.8%	7
Average	**92.6%**	

ALL DATA IS PROVISIONAL & CONTINUALLY BEING UPDATED

Table 2: All cases reported and follow ups to 18.11.2015

		VALID		INVALID				(as % of total)		
Cond	Start	C/R	D	E	X	TOTAL		C/R	D&E	X
HIV	1986	8,422	850	754	1,342	11368		74	14	12
CR	1990	92	39	65	0	196		47	53	0
PIND	1997	2214	498	1023	212	3947		56	39	5
SYP	2010	52	35	27	16	130		40	48	12
HUS	2011	191	173	103	134	601		32	46	22
KAW	2013	481	99	96	205	881		55	22	23
HEP	2014	69	8	29	7	113		61	33	6
GBS	2014	509	107	53	142	811		63	20	18
EPM	2014	378	23	62	75	538		70	16	14
EBT	2014	79	21	5	45	150		53	17	30
RKT	2015	42	2	26	45	115		37	24	39
T2D	2015	35	3	4	41	83		42	8	49
BEH	2015	12	1	6	39	58		21	12	67
ARF	2015	0	0	1	28	29		0	3	97
VIB	2015	0	0	1	17	18		0	6	94
Total		**12449**	**1859**	**2255**	**2348**	**19038**		**66**	**22**	**12**

HIV Human immunodeficiency virus in childhood
CR Congenital rubella
PIND Progressive intellectual & neurological deterioration
SYP Congenital syphilis
HUS Haemolytic uraemic syndrome
KAW Kawasaki Disease
HEP Acute Symptomatic Hepatitis
GBS Group B streptococcal disease
EPM Enterovirus and parechovirus meningitis
EBT Exchange blood transfusion
RKT Nutritional Rickets
T2D Type 2 Diabetes
BEH Behcet's
ARF Acute Rheumatic Fever
VIB Visual impairment & blindness

C/R = confirmed/already known

D = duplicate

E = reporting error or revised diagnosis

X = status not yet reported to BPSU by investigator