Twenty years of active paediatric surveillance in the the UK and Republic of Ireland

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In July 2006 the British Paediatric Surveillance Unit (BPSU, http://bpsu.inopsu.com/) celebrated its twentieth year of surveillance. The unit was founded in 1986 by the Public Health Laboratory Service (now the Health Protection Agency), the Royal College of Paediatrics and Child Health, the Institute of Child Health (London), the Royal College of Physicians (Ireland) and the Scottish Centre for Infection and Environmental Health (now Health Protection Scotland). The unit's aim was, and is, to undertake surveillance of rare conditions in childhood (0 to 15 years), including infections, and to provide a mechanism to rapidly investigate acute public health events affecting children.[1] The unit was created to address concerns from paediatricians and communicable disease consultants that conditions such as Reye's syndrome, haemolytic uraemic syndrome (HUS), Kawasaki disease and the then newly emerging condition of paediatric-AIDS were not being reported to existing 'passive' surveillance systems in sufficient numbers to enable meaningful analyses of data. The BPSU therefore set about establishing an 'active' surveillance system, seeking monthly reports from all consultant paediatricians in the United Kingdom and Ireland. Clinicians are asked to report any cases from a menu of conditions listed on the monthly report card and are asked to choose 'nothing to report' if no cases had been seen.

This active surveillance system has encompassed over 70 conditions during its first 20 years of operation, many of which have been related to infection. Compliance with reporting to the system has been high, with an average of over 90% of monthly reports completed per year.[1] The effectiveness of the BPSU's surveillance methodology has had a major impact on national policy on infectious diseases and related conditions. The BPSU has made important contributions to the monitoring of childhood diseases targeted by vaccination programmes as well as the safety of vaccines. Findings from reports of meningoencephalitis after MMR contributed to the withdrawal of the Urabe strain of the vaccine's mumps component [2]. Reports of congenital rubella contribute to monitoring the effectiveness of the national immunisation programme and the impact of the recent decline in coverage of MMR vaccination in the UK [3]. Surveillance of subacute sclerosing panencephalitis undertaken through the BPSU over 15 years, has provided good evidence that this known complication of measles infection is not associated with receipt of the measles component of the MMR vaccine [4]. BPSU data have contributed to evaluation of the effectiveness of the newly introduced Haemophilus influenzae b vaccine. Finally, a study of the incidence and severity of varicella infection in children admitted to hospital provided a baseline of the disease burden due to this infection in the pre-vaccination era and contributed to informing the development of national vaccination policy [5].

Throughout its history the BPSU has also provided a mechanism for responding to and investigating emerging public health concerns. Emerging diseases are usually rare and may remain unrecognised, potentially allowing the condition to spread. The HUS survey, undertaken in the 1980s through the BPSU, was one of the first studies to confirm the link between Escherichia coli 0157 and paediatric HUS in the UK. The study was replicated in the late 1990s in response to the Pennington Report [6], which highlighted the effectiveness of the BPSU methodology in identifying *E. coli* 0157 outbreaks. In 1997, a BPSU study clarified that diagnosed hepatitis C in children was largely the result of horizontal transmission through blood products rather than vertical transmission from mother to child [7]. More recently, childhood tuberculosis and malaria infection have been included in BPSU surveillance. In response to public health concern about the potential impact of variant Creutzfeld-Jakob disease (vCJD) on children in the UK, the BPSU is currently undertaking surveillance for cases of progressive intellectual and neurological deterioration in order to identify cases of vCJD and has reported six cases in children since 1997 [8].

Findings from the BPSU have influenced national screening policies. The BPSU's surveillance of HIV in children contributed to the policy introduced in England in 2000 to offer antenatal screening to all pregnant women [9]. Information about disease prevalence and the burden of disease for other neonatal and congenital infections, such as toxoplasmosis, herpes simplex and Group b streptococcal infections, has contributed to decisions not to initiate screening programmes for these conditions.

In summary, on review after 20 years of operation, there is evidence that the system is acceptable, sustainable and is producing high quality data about a range of relatively rare but important childhood conditions that are informing and influencing a variety of activities concerned with child health in the UK. The success of the BPSU surveillance system has encouraged similar surveillance schemes in the UK and abroad. In 1998, the International Network of Paediatric Surveillance Units (INoPSU, http://www.inopsu.com/) was established. This network now covers 14 countries (including eight within the European Union), and involves 10 000 paediatricians covering a population of 50 million children [10].

References:

- Nicoll A, Lynn R, Rahi J, Verity C, Haines L.Public Health Outputs from the British Paediatric Surveillance Unit and similar clinician-based surveillance mechanisms. J R Soc Med 2000; 80:580-585.
- Maguire HC, Begg NT, Handford SG. Meningoencephalitis associated with MMR vaccine. CDR (Lond Engl Rev). 1991 May 24:1(6):R60-1.
- Tookey P. Rubella in England, Scotland and Wales. Surveillance Report. Eurosurveillance Monthly 2004; 9(4):21-22. Available 3.
- from http://www.eurosurveillance.org/em/v09n04/0904-231.asp%20 C Miller, N Andrews, M Rush, H Munro, L Jin, E Miller. The epidemiology of subacute sclerosisng panencephalitis in England and Wales 1990-2002. Arch Dis Child. 2004;89(12):1145-8

- 5. Bramley C.Severe complications of varicella in hospitalised children. In BPSU 18TH Annual Report 2003-2004. Chpt 5 pg 28-29.
- London 2004

 Advisory Committee on the Microbiological Safety of Food. Report on Vero cytotoxin-producing Escherichia coli. 1985 London: 6. HMSO.
- 8.
- 9.
- HMSO.

 Gibb DM, Neave PE, Tookey PA, Ramsay M, Harris H, Balogun K, Goldberg D, Mieli-Vergani G, Kelly D. Active surveillance of hepatitis C infection in the UK and Ireland. Arch Dis Child. 2000 Apr; 82(4):286-91

 Verity C, Nicoll A, Will RG, Devereux G, Stellitano L. Variant Creutzfeldt-Jacob disease in UK children a national surveillance study. Lancet 2000; 356: 1224-7

 NHS Executive. Reducing mother to baby transmission of HIV.Health Service Circular 1999/183. Department of Health: London,August 1999. (http://www.dh.gov.uk/assetRoot/04/01/21/28/04012128.pdf)

 Eliott EJ, Nicoll A, Lynn R, Marchessault V, Hirasing R, Ridley G. Rare disease surveillance: An International Perspective. Paediatr Child Health 2001; 6(5): 251-260 10.