

Public health outputs from the British Paediatric Surveillance Unit and similar clinician-based systems

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The British Paediatric Surveillance Unit (BPSU) started life in 1986¹. The stimulus for its creation was twofold—the seeming incompleteness of existing passive surveillance systems, reporting various specific infection-related conditions; and a growing burden on paediatricians from investigators asking for reports on these and other rare conditions. The unit was therefore conceived as an active surveillance mechanism and an efficient way of focusing reporting through a single channel¹. Its prime owner has been paediatricians, through the British Paediatric Association, which became the Royal College of Paediatrics and Child Health (RCPCH) in 1996, and in whose headquarters the Surveillance Unit office has been based. However, the BPSU also represents a partnership involving other institutions—namely, the Public Health Laboratory Service, the Institute of Child Health (London) and the Scottish Centre for Infection and Environmental Health.

In nearly a decade and a half the unit has been used to undertake over forty studies in the 12–13 million child population of the UK and Eire. These represent over 2100 study-months, detecting over 16 000 cases of rare conditions and contributing wholly or partly to more than one hundred publications in peer-review journals. A measure of its success is imitation, and the BPSU methodology has been adopted by other UK specialties, with surveillance among obstetricians (for HIV), ophthalmologists, specialists in genitourinary medicine (for syphilis), gastroenterologists and neurologists by, respectively, the Royal College of Obstetricians and Gynaecologists², the Royal College of Ophthalmologists³, the British Co-operative Clinical Group (genitourinary medicine)⁴, the British Society of Gastroenterology⁵ and the British Neurological Surveillance Unit⁶. It has also been imitated abroad, with nine other countries having very

similar paediatric units (Table 1) which since 1998 have been in the International Network of Paediatric Surveillance Units⁷. The BPSU serves multiple purposes, allowing paediatricians to undertake and contribute to surveillance but also informing them about rare conditions and responding to public health emergencies such as the advent of variant Creutzfeldt-Jakob disease⁸. The specific studies undertaken have covered many areas of child health including infections, metabolic conditions, rare inherited disorders, neurological conditions, accidents and injuries (Box 1). Public health importance has always been one of the prime criteria that the unit's executive committee considers when deciding whether or not to accept a proposal. In this paper we review the public health outputs from studies undertaken through the BPSU and similar units in the UK. Unless stated otherwise, the studies cited have been conducted through the BPSU.

METHODS

The mechanism of the BPSU, outlined in Figure 1, is described in detail elsewhere^{1,9}. It can be characterized as an efficient postal system which allows the simultaneous and efficient running of multiple surveillance projects whilst limiting the burden of reporting on individual doctors. The system is active surveillance through monthly distribution of an eye-catching orange card (Figure 2) sent to every paediatrician of consultant status currently seeing patients in the UK or Eire. Their contact details are maintained in an active database in the BPSU office reconciled at intervals with the database of RCPCH members. Through the orange card, respondents are asked whether they have seen any case of up to 14 rare conditions in the preceding month. The card is returned to the BPSU office whether or not one of the conditions has been seen and a remarkable statistic is that, after 14 years, over 90% of doctors still return their orange card to the BPSU every month¹⁰. Most months, most doctors will make a 'nil return', but when the occurrence of a case is reported on a card the BPSU office tells the appropriate investigator the name of the paediatrician concerned. The investigator then sends him

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Table 1 National paediatric surveillance units

	Began	Child population (million aged 1-15 years)	Respondents	Average response rate 1999
Australia	1993	3.9	985	96%
UK & Eire	1986	12.8	2025	93%
Canada	1996	6.0	2210	83%
Germany	1992	13.0	468	94%
Latvia	1996	0.4	22	94%
Malaysia	1992	7.6	395	75%
Netherlands	1994	2.8	432	91%
New Zealand	1997	0.8	165	94%
Papua New Guinea	1996	1.9	40	79%
Switzerland	1995	1.3	40 clinics	99%
Wales	1994	0.65	134	95%

Box 1 Conditions studied through British Paediatric Surveillance Unit

Acute flaccid paralysis (polio)	Galactosemia	Necrotizing enterocolitis (neonatal)
Androgen insensitivity syndrome	Haemolytic uraemic syndrome	Neonatal herpes
Cerebral oedema following DKA	Haemophagocyte lymphohistiocytosis	Neonatal meningitis
Chemistry-set poisoning	Haemorrhagic disease of the newborn	Parenteral nutrition (long-term)
Congenital brachial palsy	Hepatitis C	PIND/CJD
Congenital cataracts	Higher order births	Pyridoxine-dependent seizures
Congenital dislocation of the hip	HIV/AIDS	Rheumatic fever
Congenital rubella syndrome	Inflammatory bowel disease	Rett's syndrome
Congenital syphilis	Invasive <i>Haemophilus influenzae</i> b infection	SSPE
Congenital toxoplasmosis	Juvenile dermatomyositis	Streptococcal infection
Diabetes in children	Kawasaki disease	Visual impairment
Drowning and near drowning	Lowe's syndrome	Vitamin K deficiency
Encephalitis 2-36 months	MMR associated meningitis	Water-births
Fatal/severe allergic reaction	Munchausen-by-proxy syndrome	

DKA=diabetic ketoacidosis; MMR=mumps/measles/rubella vaccine; PIND/CJD=progressive intellectual and neurological deterioration/Creutzfeldt-Jakob disease; SSPE=subacute sclerosing panencephalitis

or her a data collection proforma (reviewed by the BPSU Executive for brevity, relevance and confidentiality) for completion. No patient information is passed to the BPSU itself, and the proformas conform to Caldicott principles¹¹, capturing only the patient information required to achieve study aims. Increasingly, patient identifying data are anonymized—i.e. no names are sent to investigators. Sometimes the elimination of duplicates and linkage of datasets still requires names, but the need will become less as NHS numbers come into wider use. To improve the completeness, accuracy and validity of their data most studies reconcile the detail of the reports with other sources—for example, laboratory reports for studies on infections.

PUBLIC HEALTH OUTPUTS

Informing policy decisions on screening

An innovation of the 1990s was the establishment of a UK National Screening Committee (NSC)¹². The initial core

job of the NSC has been making decisions on the initiation (or not) of screening for over two hundred conditions proposed as screening candidates in addition to considering the quality and value of existing screening programmes¹³. Dr Muir Gray (the NSC's scientific secretary) has characterized this role as 'Starting starting, starting stopping, stopping starting and stopping stopping... of screening'. Data derived through the BPSU and its equivalents have contributed substantially to those decisions (Table 2). In the 1990s surveillance for paediatric AIDS revealed considerable numbers of children vertically infected with HIV from their mothers, in the UK¹⁴. For many of these children the development of a life-threatening AIDS-defining condition was seemingly the first occasion that the mother's infection was known about (Figure 3). This and the appreciation that it was possible to prevent vertical infection almost entirely (also measurable via the BPSU¹⁵) generated pressure for change. The impact was seen first in professional approaches, then in government attitudes and finally in the introduction of a

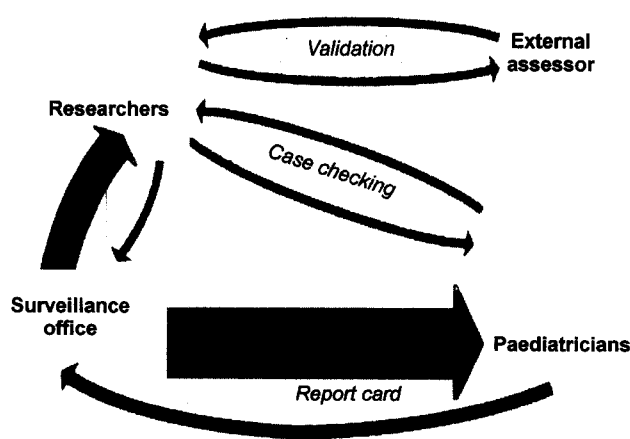


Figure 1 Methodology

policy of routine screening with defined targets in England^{16,17}. By contrast, surveys for vertically acquired toxoplasmosis and neonatal herpes indicated that the incidence of neonatal disease was too low to justify initiation of screening in pregnancy for either new maternal toxoplasmosis infections or active genital herpes^{18,19}. Surveillance for syphilis in pregnancy (through genitourinary medicine specialists) and congenital syphilis revealed a continuing burden of infectious syphilis in mothers and with other data led to a decision by the National Screening Committee to continue antenatal syphilis screening^{4,20}.

BPSU derived data have also informed screening for non-communicable disorders. The physical examination of all newborn and young infants is a long established and universal screening practice in the UK. Two of the main target disorders, congenital dislocation of the hip (CDH) and congenital cataract have both been surveyed through the BPSU, as well as through disorder-specific orthopaedic and ophthalmic clinician-based reporting schemes, respectively. The CDH survey showed that the incidence of first operative procedure for CDH has not changed since screening was introduced, and most children requiring surgery do not seem to be detected through the formal

screening examination²¹. The cataract survey indicated that less than half of all children newly diagnosed with congenital cataract were detected through the routine newborn or 6–8 week examination intended to detect this disorder. This identified a need for improvements in the routine ophthalmic examination of infants, especially in the training of those responsible²². Together these findings have informed NSC recommendations regarding the need to improve the quality of established practice nationally and to consider alternative strategies for improving early detection of both disorders. Surveillance data are also used to monitor screening programmes continuously. Surveillance via the Royal College of Obstetricians and Gynaecologists' system allows the continuous monitoring of the effectiveness of antenatal HIV screening to detect HIV in pregnant women²³.

Table 2 Informing policy decisions on antenatal infection screening

	Condition	Input
Start starting	HIV	PHLS/ICH(L)/SCIEH
Start stopping	—	—
Stop starting	Toxoplasmosis	ICH(L)/PHLS
	Herpes	ICH(L)/PHLS
Stop stopping	Syphilis	St Mary's/PHLS/BCCG

ICH(L)=Institute of Child Health, London; PHLS=Public Health Laboratory Service; BCCG=British Co-operative Clinical Group

Providing information for clinical governance

A survey of children with biliary atresia revealed important differences in outcome for this condition according to the size of the unit undertaking surgery and the number of cases operated upon (with centres handling more cases showing better outcome)²⁴. This led to an NHS Executive directive restricting the number of centres where surgery could be undertaken²⁵. In contrast a study of water-births was reassuring, yielding no evidence that this practice heightens the risk of mortality or morbidity²⁶. A study of Munchausen-syndrome-by-proxy revealed major differences in regional incidence and therefore raised questions of clinician awareness of this condition²⁷. Surveillance of Reye's syndrome began in 1981, with a risk factor study showing an association between Reye's syndrome and consumption of aspirin. Findings from this and other studies led to a ban on the use of aspirin in children under 12 years. Subsequent monitoring showed almost total elimination of Reye's syndrome in the UK, at least before the teenage years²⁸.

Monitoring the progress of public health interventions

Several ongoing investigations directly monitor the effectiveness of immunization programmes. The occurrence

British Paediatric Surveillance Unit Report Card

June 1999 [9906]

Nothing to Report **CODE No []**
If case (s) seen, identify how many

1. HIV & AIDS <input type="checkbox"/>	5. Fatal/severe allergic reactions to food ingestion <input type="checkbox"/>
2. Haemophilus influenzae infections 01865 221068/01865 220859 <input type="checkbox"/>	6. Subdural haematoma/effusion in under two year olds <input type="checkbox"/>
3. Haemolytic uraemic syndrome 0208 200 6868 ext 4551 (E/W, Eire) 0141 300 1180 ext 1227 (Scotland) <input type="checkbox"/>	7. Inflammatory bowel disease in under 20 year olds <input type="checkbox"/>
4. Progressive intellectual & neurological deterioration <input type="checkbox"/>	8. Encephalitis in under 3's 0207 504 9134 <input type="checkbox"/>
9. Congenital Rubella <input type="checkbox"/>	10. Reye's Syndrome <input type="checkbox"/>
	11. SSPE <input type="checkbox"/>

Figure 2 Orange card. SSPE=subacute sclerosing panencephalitis

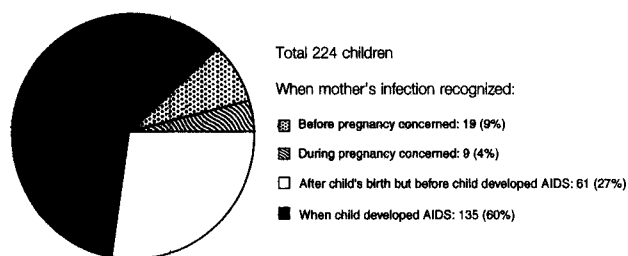


Figure 3 AIDS diagnosis in vertically infected children born in the UK (data to January 1999). Source: voluntary confidential reporting by obstetricians (RCOG), paediatricians (BPSU/RCPC) and laboratories (CDSC/PHLS)

of rare vaccine-preventable infections or their sequelae can reveal both general weaknesses in immunization programmes (for example, heightened vulnerability in recent migrants²⁹) and reasons why vaccination failed in some children but not others. Surveys for subacute sclerosing panencephalitis (SSPE) (measles vaccination), congenital rubella syndrome (CRS) and invasive *Haemophilus influenzae* type b (Hib) infection monitor the occurrence of these sentinel conditions. All these reports are strengthened by combination of clinician and laboratory reporting. SSPE reporting indicates that this rare condition results from wild measles, not vaccination³⁰. Surveillance for CRS²⁸ and Hib has indicated the general success of immunization programmes; in the case of Hib it confirms that the UK's strategy (unique in Europe) of not boosting vaccination around school entry was not prejudicing immunity³¹. The latter study also indicated that, where vaccination failed, many of the children had an underlying predisposing disorder³¹.

Identifying and quantifying public health issues

Several studies have derived estimates of the population incidence of important conditions, as a basis for identifying those at greatest risk, providing services and planning further research on aetiology and treatment. Whilst other approaches (for example, use of data routinely collected through the Office for National Statistics or Hospital Episode Statistics System) can yield simple statistics, the advantage of the BPSU mediated studies is that they efficiently capture essential clinical, social and other data, enabling the potential for health gain to be highlighted together with possible aetiological links. Such BPSU mediated studies have proved especially useful for non-communicable disorders^{22,24,32-36}. Various aspects of accidental and non-accidental injury in children, such as poisoning³⁴, subdural haematoma³⁵ and drowning³⁷, have been quantified. For example, surveillance for accidental poisoning from toy chemistry sets confirmed concerns

about problematic packaging and led to amendments in European Union legislation on toy safety³⁴. Two BPSU surveys identified diabetes mellitus as an increasingly important disorder of childhood with attendant future public health implications, and contributed to hypotheses about aetiology³². All these studies of non-communicable disorders have involved analyses that would be impossible without clinician reporting.

Responding to public health emergencies

The final aim of the BPSU has been to respond to public health emergencies. Three examples are water-births, variant Creutzfeldt-Jakob disease (vCJD) and haemorrhagic disease of the newborn (vitamin K deficiency bleeding). The common feature of these three diseases was a sudden recognition of their potential public health importance and a consequent need to determine their extent. For water-births there was concern that a vogue for delivering babies in birthing pools might increase perinatal morbidity and mortality. A surveillance study, combined with a postal survey assessing the extent of the practice, yielded no evidence of increased risk²⁶. The emergence of vCJD in young adults in 1996³⁸ raised a question of whether the condition was occurring in children. This was particularly difficult to investigate because the phenotype of vCJD in children was not obvious. Would it be like that in adults, or might it be somewhat different⁹? The approach taken was to look for all cases of progressive intellectual and neurological deterioration in children and to have an expert group of paediatric neurologists examine anonymized information from the cases. This exercise has confirmed that, though vCJD does occur in childhood, there is no evidence of an epidemic in children⁸. Haemorrhagic disease in the newborn, a topic previously investigated through the BPSU³⁹, required a further look because of changes in practice. For some years there has been concern that injected vitamin K might be associated with an increased incidence of certain cancers of childhood⁴⁰. Further studies did not resolve these concerns⁴¹, so in the late 1990s oral preparations of vitamin K began to be used in preference to injectables. This raised the possibility of an increased incidence of haemorrhagic disease because of ineffective therapy—hence the need to repeat the earlier study. All three of these 'emergency' investigations were sponsored by the Department of Health.

DISCUSSION

An advantage of the BPSU is that it allows multiple studies to be undertaken simultaneously¹, at much less cost than a series of individual studies. It is also an efficient mechanism for the reporting doctor, who fills in just one card per month. Paradoxically, however, surveillance units such as

the BPSU have difficulty in raising money because many funding bodies prefer to support individual studies. Another issue that arises is the competition for places on the small orange card between new short-term studies and ongoing surveillance for important conditions where clinicians are either the only or the most convenient source of data.

The scope for continuing and extending the work undertaken through the BPSU and its equivalents is considerable. However, there is one black cloud on the horizon. The Data Protection Act 1998, the common-law duty of confidence, some guidance from the General Medical Council and the Human Rights Act have raised the notion that doctors should always obtain explicit patient or parental consent before sharing with other health professionals identifiable data required for public health surveillance. On existing evidence, this could mean loss of between 40% and 60% of reports. This is not because of refusals from parents or patients but because of the workload such requirements place on doctors. An example is the combined surveillance and research study undertaken by the RCPCH's Research Unit and the Surveillance Unit of the Royal College of Ophthalmologists on retinopathy of prematurity. Parental consent was necessary because the research phase of the study involved seeking parents' views about the information they were given about the condition. 180 cases were initially reported via a BPSU-like mechanism, and then parental consent had to be obtained. The data collection process was considerably delayed, and initially consent was obtained for only 22% of the cohort. After a year the proportion with consent was 46% and three months after closure of recruitment it was 62%. There were only 3 cases where parents refused consent. For the 112 cases where consent was obtained it took on average two months, but for 12 cases it took between six and twelve months. Though with further reminders the proportion has risen, this was achievable only because the surveillance study had revealed there were cases to be pursued. Other surveillance and reporting schemes have had similar experiences when consent was required⁴². The BPSU Executive is concerned that, if explicit consent had to be sought from parents before a case was reported to the BPSU, then key information required to protect the health of children would not be obtained in the future. Current examples of conditions for which surveillance would be stopped or severely curtailed are HIV and AIDS, vaccine preventable diseases, rare adverse consequences of vaccination, vCJD, subdural haematoma (commonly a result of child abuse) and haemorrhagic disease of the newborn. Outside of the BPSU system, surveillance for meningococcal disease and haemolytic-uraemic syndrome would be similarly affected. Where we should look for guidance on how to proceed in this important area, so that public health surveillance is not prejudiced, is not yet clear⁴².

Acknowledgment The foundation of the BPSU, and of its success, is its constituency and the investigators who use it. We acknowledge the tireless efforts of paediatricians who support the unit by returning orange cards and completing reports, and of the investigators who undertake the many studies.

REFERENCES

- Hall SM, Nicoll A. The British Paediatric Surveillance Unit—a pioneering method for investigating the less common disorders of childhood. Report of a seminar held in June 1995. *Child Care, Health Development* 1998;24:129–43
- Ades AE, Davison CF, Holland FJ, *et al.* Vertically transmitted HIV infection in the British Isles. *BMJ* 1993;306:1296–9
- Rahi JS, Edelsten C. The British Ophthalmological Surveillance Unit. *Eye* 1998;11:766–7
- Hurtig A-K, Nicoll A, Carne C, *et al.* Syphilis in pregnant women and their children in the United Kingdom: results from national clinician reporting surveys 1994–7. *BMJ* 1998;317:1617–19
- Mian S. British Society of Gastroenterology Research Unit. Methodology and activities. RCPCH/RCPCH Joint symposium, Edinburgh, 1999
- Cockerell OC, Gupta S, Catchpole M, Sander JW, Shorvon SD. The British Neurological Surveillance Unit: a nation-wide scheme for the ascertainment of rare neurological disorders. *Neuroepidemiology* 1995;14:182–7
- Elliott E, Nicoll A, Lynn R, Marchessault V, Hirasings R (INoPSU Secretariat), on behalf of INoPSU members. An international network of paediatric surveillance units: a new era in monitoring uncommon diseases of childhood. *Paediatr Child Health* (in press)
- Verity C, Nicoll A, Will R, Devereux G, Stellitano L. Variant Creutzfeldt-Jakob disease in UK children: a national surveillance study. *Lancet* 2000;356:1224–7
- Hall S, Glickman M. Report of the British Paediatric Surveillance Unit. *Arch Dis Child* 1989;64:439–40
- British Paediatric Surveillance Unit 14th Annual Report* 1999. London: RCPCH, 2000
- Caldicott Committee. *Report on the Review of Patient-identifiable Information*. NHS Executive, December 1997
- Calman K. Developing screening in the NHS. *J Med Screening* 1994; 1:101–5
- National Screening Committee. *First Annual Report*. Health Departments of the United Kingdom, April, 1998
- Nicoll A. Antenatal screening for HIV in the UK: what is to be done? *J Med Screening* 1998;5:170–1
- Duong T, Ades AE, Gibb DM, Tookey PA, Masters J. Vertical transmission rates for HIV in the British Isles: estimates based on surveillance data. *BMJ* 1999;319:1227–9
- Intercollegiate Working Party for Enhancing Voluntary Confidential HIV Testing in Pregnancy (Royal Colleges of General Practitioners, Midwives, Nursing, Obstetricians & Gynaecologists, Pathologists, Paediatrics & Child Health and Physicians; Public Health Laboratory Service; Faculty of Public Health Medicine, Directorates of Public Health of North & South Thames). *Reducing Mother to Child Transmission of HIV Infection in the UK*. London: Royal College of Paediatrics & Child Health, 1998
- Department of Health. *Health Service Circular* 1999/183
- Peckham CS, Logan S. Screening for toxoplasmosis during pregnancy. *Arch Dis Child* 1993;68:3–5
- Tookey PA, Peckham CP. Neonatal herpes simplex virus infection in the British Isles. *Paediatr Perinat Epidemiol* 1997;10:432–42
- Welch J. Antenatal screening for syphilis. *BMJ* 1998;317:1605–6

- 21 Godward S, Dezateux C, on behalf of the MRC Working Party on Congenital Dislocation of the Hip. Surgery for congenital dislocation of the hip in the UK as a measure of outcome of screening. *Lancet* 1998;**351**:1149-52
- 22 Rahi JS, Dezateux C, for the British Congenital Cataract Interest Group. National cross-sectional study of detection of congenital and infantile cataract in the United Kingdom: role of screening and surveillance. *BMJ* 1999;**318**:362-5
- 23 Communicable Disease Surveillance Centre, Scottish Centre for Infection and Environmental Health, Institute of Child Health (London), & Oxford Haemophilia Centre. AIDS and HIV-1 infection in the United Kingdom: monthly report HIV infection in pregnant women giving birth in the UK—levels of infection and proportions diagnosed. *Commun Dis Rep* 2000;**10**:77-80
- 24 McKiernan JP, Baker AJ, Kelly D. The frequency and outcome of biliary atresia in the UK and Ireland. *Lancet* 2000;**355**:25-9
- 25 National Specialist Commission Advisory Group. *Health Service Circular* 1999/132
- 26 Gilbert R, Tookey P. Perinatal mortality and morbidity among babies delivered in water: surveillance study and postal study. *BMJ* 1999;**319**:483-7
- 27 McClure RJ, Davis PM, Meadow SR, Sibert JR. The epidemiology of Munchausen syndrome by proxy, non-accidental poisoning and non-accidental suffocation. *Arch Dis Child* 1996;**75**:57-61
- 28 Porter JDH, Robinson PH, Glasgow JFT, Banks JH, Hall SM. Trends in Reye's syndrome and aspirin use. *Arch Dis Child* 1990;**65**:826-9
- 29 Tookey PA, Peckham CS. Surveillance of congenital rubella in Great Britain 1971-1996. *BMJ* 1999;**318**:769-70
- 30 BPSU. Subacute sclerosing panencephalitis (SSPE). In: *British Paediatric Surveillance Unit 14th Annual Report*. London: RCPCH, 1999
- 31 Booy R, Heath PT, Slack MPE, Begg N, Moxon ER. Vaccine failures after primary immunisation with *Haemophilus influenzae* type-b conjugate vaccine without booster. *Lancet* 1997;**349**:1197-202
- 32 Metcalfe MA, Baum JD. Incidence of insulin dependent diabetes in children aged under 15 years in the British Isles during 1988. *BMJ* 1991;**302**:443-7
- 33 Kemp AM, Sibert JR. Outcome in children who nearly drown: a British Isles study. *BMJ* 1991;**302**:931-3
- 34 Mucklow ES. Chemistry set poisoning. *Int J Clin Pract* 1997;**51**(5):321-3
- 35 BPSU. Subdural haematoma/effusion. In: *British Paediatric Surveillance Unit 14th Annual Report*. London: RCPCH, 2000
- 36 BPSU. Anaphylaxis. In: *British Paediatric Surveillance Unit 14th Annual Report*. London: RCPCH, 2000
- 37 Kemp AM, Sibert JR. Drowning and near drowning in children in the United Kingdom: lessons for prevention. *BMJ* 1992;**306**:291-7
- 38 Will RG, Ironside JW, Zeidler M, et al. A new variant of Creutzfeldt-Jakob disease in the UK. *Lancet* 1996;**347**:921-5
- 39 McNinch AW, Tripp JH. Haemorrhagic disease of the newborn in the British Isles: a two year prospective study. *BMJ* 1991;**303**:1105-9
- 40 Golding J, Greenwood R, Birmingham K, Mott M. Childhood cancer, intramuscular vitamin K, and pethidine given during labour. *BMJ* 1992;**305**:341-6
- 41 von Kries R. Neonatal vitamin K prophylaxis: the Gordian knot still awaits untying. *BMJ* 1998;**316**:161-2
- 42 BPSU Executive. *The British Paediatric Surveillance Unit (BPSU) and Patient Confidentiality*. London: BPSU, 1999