

SHORT REPORT

Is regional paediatric surveillance useful? Experience in Wales

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Abstract

The Welsh Paediatric Surveillance Unit was established in 1994 to monitor the incidence and prevalence of a number of uncommon disorders of childhood in Wales. Its work complements that of the British Paediatric Surveillance Unit. Information from consultant paediatricians is obtained by means of a monthly card return system; return rate is over 90%.

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The identification and surveillance of rare conditions in childhood has long been an aim of those promoting child health. In 1986, the British Paediatric Surveillance Unit (BPSU)^{1 2} began enabling paediatricians to participate in the surveillance of infectious disease and uncommon disorders in childhood. It uses a monthly card return system to consultant paediatricians and has been the stimulus for a number of other national surveillance systems throughout the world.³ We believed there was a need for a child health surveillance system that was available for the devolved Health Service in Wales, both for public health and health management issues, and for audit and research. To address this the Welsh Paediatric Surveillance

Unit (WPSU) was established in 1994 to complement the work of the BPSU.

Methods and results

The WPSU uses the same methodology that had been successful with the BPSU.^{1 2} The cards are green with a daffodil symbol to prevent confusion. Cards are distributed each month to consultant paediatricians and senior clinical medical officers in Wales (there are approximately 100) and are sent back even if there are no cases to report. The appropriate investigator is informed, who contacts the reporting paediatrician for further information. Table 1 shows the 17 projects that have been accepted by the WPSU and estimates of their incidence or prevalence. Studies have provided information on health care planning, audit, and research.

We have assessed the usefulness of the WPSU according to guidelines published by the Centers for Disease Control in Atlanta.⁴ It has fulfilled the majority of the criteria. Only two of the studies failed to complete. The researchers of the 10 studies completed judged them as providing valuable results. The studies on renal failure at the start of the WPSU needed extra ascertainment from other sources.

As a result of our work, actions have been taken on the health of children in Wales. They have included the establishment of a paediatric

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Table 1 WPSU projects

Project	Researcher	Study number	Incidence in Wales* (per 100 000)	Start date	Finish date
Acute renal failure	Kate Verrier-Jones	1	5.0 (CI ± 1.6)	01/07/94	30/9/97
Congenital adrenal hyperplasia	John Gregory	2	6.7 (CI ± 1.1) (prevalence 0-18 years)	01/07/94	31/12/99
Household product poisoning	Jo Sibert	3	Unsuccessful	01/07/94	31/03/95
Chronic renal failure	Kate Verrier-Jones	4	9.3 (CI ± 1.1)	01/07/94	30/09/97
Coeliac disease	Huw Jenkins	5	2.4 (CI ± 0.9)	01/01/95	28/02/97
			New cases		
Haemoglobinopathy	Marianne Phillips	6	Unsuccessful	01/01/95	28/02/97
Inflammatory bowel disease	Huw Jenkins	7	2.1 (CI ± 0.8)	01/01/95	28/02/97
			New cases		
The critically ill child	Graham Shortland	8	20.7 (CI ± 2.4) (0-16 years)	01/10/95	30/09/97
Severe physical child abuse	Jo Sibert	9	114 CI ± 11.8) (babies under 1)	01/01/96	31/03/98
			All physical abuse		
Childhood tuberculosis	Mazin Alfaham	10	1.6 (CI ± 0.6) (confirmed cases)	01/09/96	Ongoing
			2.0 (CI ± 0.7) (chemoprophylaxis)		
Marfan's syndrome	Graham Stuart, then Sally Davies	11	0.4 (CI ± 0.28)	01/09/96	30/6/00
			New referrals		
Children in house fires	Jean Matthes, Swansea	12	23.0 (CI ± 3.8)	01/01/98	31/12/99
Subdural haemorrhage	Alison Kemp	13	34.0 (CI ± 19.2) (babies under 6 months)	01/01/98	31/03/98
Newly diagnosed diabetes	Mike Maguire	14	Not yet available	01/07/98	Ongoing
Newly diagnosed malignant disease	Meriel Jenney	15	10.0 (CI ± 2.5)	01/01/99	31/12/00
Subdural haemorrhage	Alison Kemp	16	34 (CI ± 19.2) (babies under 6 months)	01/04/99	Ongoing
Facial palsy	Catherine Norton	17	Not yet available	01/01/00	Ongoing

*0-13 years unless stated.

intensive care unit in Wales and management criteria for subdural haematoma. We have found the WPSU simple to manage, as it is part of the Welsh Paediatric Society. The positive card returns indicate that Welsh paediatricians have accepted it. The National Assembly for Wales has also accepted it for partial central funding.

We have analysed card returns from the WPSU and the BPSU: both systems have good card return rates of well over 90%. Statistically, rates of card return were better with the WPSU than the BPSU in 1996 ($p < 0.001$) and 1999 ($p < 0.01$) and no different in 1997 and 1998. There has been a steady improvement in the card returns in Wales from the BPSU over the years. Comparing 1995 (93.9%) with 1999 (97.6%), the returns have improved significantly ($p < 0.001$). The ranking of Wales compared to other regions in the British Isles for the BPSU has improved from 12th of 20 regions in 1995 to first in 1999.

Conclusions

The WPSU has now been in existence for six years. We have shown that the system works and that we are now accepted as useful by Welsh paediatricians and also by the National Assembly. Paediatricians return their cards at a

similar (and indeed better) rate to the UK BPSU system. We believe that "ownership" of the project by Welsh paediatricians has been vital for its success. Response rates in Wales to the BPSU have improved during the existence of the WPSU and we believe that the WPSU could have improved the understanding and appreciation of Welsh paediatricians in surveillance. We believe it could be a model for similar work in the UK and in European countries with small child populations.

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