A special conditions register

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Abstract

A special conditions register (SCR) linked to the child health system's register of all children has been in use in West Sussex since 1977. This paper describes the aims, organisation, and use of the SCR and gives examples of the aggregated data that may be obtained. Of the 155 000 children aged 0-17 resident in West Sussex in 1990, 4.3% were included on the SCR. Altogether 45.7% of children on the SCR had physical conditions with mild or no disability and 17.2% had moderate educational problems. The prevalence of severe hearing loss as defined was 1.7 per 1000 aged 5-17. The prevalence of diabetes mellitus was 1.2 per 1000 children aged 0-17. Validation of the SCR for diabetes mellitus found 35/36 of the eligible children were correctly registered and no child was incorrectly included. The conflicting priorities for maintaining a register for the care of individual children, for service planning, and for epidemiological research are discussed.

Background

In 1976 the Court report emphasised the need for continued surveillance of children with handicap.¹ Six years later only 78% of health authorities in England and Wales had some form of handicap register, only 12% had a computerised register,² and West Sussex had the only computerised special conditions register (SCR) which was linked to the central child register. Since then many district health authorities have developed their own stand alone computerised SCRs³ and integrated SCRs are being developed by two large groups of district health authorities⁴ for their child health systems (G Coleman. Special needs registers, 1989; unpublished).

Although the names 'handicap register', 'special conditions register', and 'special needs register' are used by different district health authorities, most reported registers include all children with ongoing significant medical and developmental problems and share the common aim of ensuring their special needs are met.²⁻⁷

Aims, development, and organisation

The three aims of the West Sussex SCR are to improve the care of individual children by ensuring that all those with ongoing medical, developmental or learning problems are identified and followed up, to monitor, evaluate, and plan services, and to facilitate epidemiological research.

Computerisation of the child health system began in 1962 in West Sussex.⁶ In 1971 the West Sussex County Council was commissioned by the Department of Health and Social Security to develop a system on the 'sun-satellite' model with a central file of the child population as the 'sun' surrounded by 'satellites' for immunisation and vaccination, early child health, school health, and special conditions (West Sussex Area Health Authority Community Health Branch. A computer assisted system for the school health service, 1972; unpublished). The SCR was set up in 1977 and special condition files were created for all children age 0-19 on the central file at that time who came within the definition.

There are three district health authorities in West Sussex: Chichester, Mid Downs, and Worthing. The community paediatrician for Chichester is responsible for maintaining the SCR for all three and for the accuracy, effectiveness, and confidentiality of the register. The district health authorities purchase computing services from the West Sussex County Council for the whole of the child health system. The system runs on an IBM 3090 mainframe computer using overnight batch processing.

Variables recorded and sources of information

A child's file on the child health system is initiated by the detailed birth notification used in West Sussex (table 1). The child's Guthrie test results, immunisation status, and results of scheduled screening throughout childhood are reported to the system by the laboratory, health visitor, general practitioner, clinical medical officer, school doctor, or school nurse. The SCR, being part of the child health system, need contain only information related to special conditions (table 2). At present up to 15 entries can be recorded for each child. As the SCR is intended to identify and classify the child, not to replace the clinical records, this has proved adequate to date even for children with multiple handicaps.

Child development teams and other health professionals such as peripatetic teachers of the deaf and educational psychologists send reports to the system. Copies are received of hospital outpatient letters, discharge summaries, letters from regional centres, and death registrations. Health visitors are required to notify the community paediatrician when a child with a significant medical or developmental problem moves into the district. Reports from health professionals other than doctors are confirmed

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Table 1 Variables recorded in the child health system from the birth notification

- Mother's age and obstetric history, including exposure to risk factors (for example, smoking, x rays) and use of medication during pregnancy
- Perinatal details, including mode of delivery, birth weight and gestation, Apgar score, postnatal jaundice, convulsions, or respiratory distress
- Birth order
- Congenital malformations
- Family history of illness—for example, tuberculosis, Down's syndrome, haemophilia
- Socioeconomic group

Table 2 Variables recorded in the SCR

- Main functional disability: physical, developmental (<5 years), educational (≥5 years), sensory vision, sensory hearing, speech, psychological, multiple
- Disability severity: none or mild (not requiring special treatment or schooling, early stages of chronic disease—for example, Still's disease, cystic fibrosis, diabetes mellitus), moderate (needing treatment or special schooling—for example, moderate learning difficulties, developmental delay with developmental quotient <70), significant (needing special schooling or increased support), or severe
- Diagnosis by ICD9 and supplementary codes
- School or unit attended
- Use of aids—for example, wheelchair or hearing aid
- Year of statement of special educational need

by hospital reports or by information obtained directly from the child's general practitioner.

In addition to this constant unscheduled updating the SCR is routinely updated every year. Each health visitor receives a list of children under 5 years of age in her practice whose names are on the SCR, to check their entry, and to identify children who should be added to or removed from the list. For school age children a list is sent for checking to each school doctor and nurse. Updating continues until the child leaves school; this will be at age 19 for many children with special educational needs. At age 20 the child's file becomes an archive file. Although children who die, move away, or improve are removed from the SCR, their data remain retrievable in the system.

Validation for diabetes mellitus

The SCR was validated in May 1990 for prevalent cases of children with diabetes mellitus living in Chichester health district and born on or after 1 January 1973. As diabetic children are almost certain to be attending hospital, consultants should be able to provide an independent external set of cases for comparison.⁸ All paediatricians and nurses receiving referrals from the district were asked to identify cases known to them.

Thirty one children with diabetes mellitus were identified, and 30 of these children had been accurately recorded on the SCR. The remaining child had previously been accurately recorded but the diagnosis of diabetes mellitus had been deleted in error when diabetes insipidus was also diagnosed at 15 years of age.

An additional five children with diabetes mellitus on the SCR were not identified by the paediatricians and nurses. Further inquiry established that all five were correctly registered. Four were over 15 and had been transferred to adult specialists, who had not been approached. The paediatrician of the remaining child did not respond.

In summary, 35 of 36 eligible children were correctly registered on the SCR and no children were incorrectly included.

Uses of the SCR

Whenever a child is seen in a scheduled consultation, the latest information from the SCR is included in the clinic record. Once a year, before confirming the SCR entries for their children, health visitors and school medical officers review each case from clinical records, by discussion with colleagues (for example teachers at special schools) or by medical examination where appropriate.

In addition, the flow of information to the SCR leads to opportunistic review of individual cases by the community paediatrician. The aim is to safeguard children against the risk of assuming all aspects of care will be covered in follow up at a regional referral centre or a local paediatric outpatients department.

The SCR is used to ensure the local authority education department has been notified by the age of 2 that a child may have special educational needs and in future it will be used to provide the social services department with the register of disabled children required under the Children Act 1989.⁹

Information for monitoring, evaluating, and planning services is sent on request and after approval by the community paediatrician to health, education, and other professionals. Recent examples include advisory teachers requesting the number of children with hearing aids, the number of visually impaired children in mainstream school, and the number of children under 5 with developmental problems who will need nursery places. Information has been provided for the Director of Public Health's Annual Report in each of the three districts.

For epidemiology, the SCR has been recently used to calculate the prevalence in West Sussex of severe sensorineural hearing loss, of severe visual defect, and of deaf-blind children. Current research includes the identification of secular change and risk factors in congenital heart disease and childhood malignancy and outcome in low birthweight babies.

Children on the SCR

In October 1990 there were 155 033 children born between 1 January 1973 and 31 December 1989, currently resident in West Sussex, and included on the child health system's register of all children. A total of 6594 children (4.2%) were included on the SCR (table 3). By severity code, 50.5% of children on the SCR had mild disability or none and 33.5% had moderate disability. By function code, 53.7% of children had physical conditions, and 21.0% were in the educational category used for children with learning difficulties aged 5 years and over. By both severity and function codes, 45.7% of children on the SCR had a physical condition resulting in mild disability or none, and 17.2% had a moderate educational problem. Severe hearing loss, an uncommon condition clearly

Table 3 Children aged 0-17 on the SCR by function and severity of disability (n=6594)

Function	Severity				Total (%)
	None or mild	Moderate	Significant	Severe	
Physical	3015	388	117	21	3541 (53.7)
Developmental	34	100	66	0	200 (3.0)
Educational	50	1132	104	99	1385 (21.0)
Vision	77	39	24	5	145 (2.2)
Hearing	91	199	36	49	375 (5.7)
Speech	51	325	75	0	451 (6.8)
Psychological	11	15	115	212	353 (5.4)
Multiple	0	8	30	106	144 (2.2)
Total (%)	3329 (50.5)	2206 (33.4)	567 (8.6)	492 (7.5)	6594 (100.0)

defined, and asthma, a common condition less well defined, are used as examples of simple aggregate data available from the SCR.

The SCR was interrogated in February 1990 for prevalent cases of severe deafness among children born from 1 January 1972 to 31 December 1984, by year of birth. There were 110 children with average hearing loss in the better ear of 50 dB or more and 82 children with multiple handicaps which included hearing loss (ICD code 389.0). The denominator of all children born in these years and currently on the child health system was 111 899, giving a prevalence of 1.7 per 1000 overall with no statistical evidence for a trend over time.

The criteria for including a child with asthma on the SCR are that (i) the child has had more than one hospital admission for asthma or requires regular courses of steroids and (ii) the child needs regular prophylaxis. In October 1990, 1211 children aged 0-17 met these criteria, or 18.4% of children on the SCR and 7.8 per 1000 children in West Sussex.

Discussion

Accuracy of population based registers of handicapped or impaired children has been found to increase with the number of sources of information, the amount of active reporting (where replies are requested whether or not there is a case to report), the length of the case finding period, and the age of preschool children. Conversely accuracy has been found to decrease with the number of variables recorded for each child, and most importantly with the mobility of the child population.¹⁰⁻¹²

The effect of mobility is to inflate a register, as it is more important for the care of the individual child to record movement in than movement out of the district.¹⁰ As there is some evidence that handicapped children move more often than other children,^{10 13} the effect of mobility is likely to overestimate the prevalence of handicap in a district health authority.

As the West Sussex SCR uses multiple sources and active reporting, and as mobility is low in the area, accuracy should be relatively high. The validation score of 35/36 for diabetes mellitus may be compared with a score of 57/68 reported in a similar validation of an SCR for diabetes mellitus elsewhere.³ The West Sussex exercise is a reminder that for older children who have transferred to adult physicians paediatricians do not provide an independent external set of prevalent cases.

Although the SCR is updated until age 19 for children who remain in school, accuracy declines after age 16 when register entries for children who have left school are no longer reviewed each year by the school medical officer, and incident cases age 16-19 may never be added to the SCR. The accuracy of the child health system as the population denominator will also fall at school leaving age. For these reasons although the SCR continues to contribute to the care of some individual children until age 19, it is unlikely to contribute to service planning and research after age 16.

The proportion of the child population included on the SCR is a function of the level of morbidity and the level of ascertainment, but is primarily determined by the policy on criteria for inclusion, for example the policy on asthma. In West Sussex these factors lead to 4.3% of children being included on the register, but in Northumberland, with a different policy, the proportion is nearer 3%.³

The outstanding advantage of an SCR, which is linked to the population register of the child health system, is that all information is immediately available for each child. For analysis of aggregate data good computer programming is also needed. The quality of programming available to the West Sussex SCR has meant that to date it has been possible to meet all requests, and yet exploitation of the potential for monitoring, planning, and evaluating services, and for facilitating epidemiological research has only just begun.

Like the Community Health Index in Scotland¹⁴ or the population register in British Columbia, Canada,¹² SCRs that form part of child population registers have considerable potential for identifying cases, controls, and risk factors for research, with appropriate safeguards for confidentiality and consent. The registers are population based and longitudinal and contain information for each child from birth with comparable information for other children from the same birth cohort, family, neighbourhood, school, treatment centre, and general practitioner.

As other studies have pointed out, however, there are problems in using a register for research which is maintained primarily for the care of individual children and for planning services.^{2 10} Priorities may conflict in keeping the register up to date and coping with the problem of mobility. For the care of an individual child addition to the register is more important than deletion. For planning services the priority is an up to date list of resident prevalent cases and their future service requirements. For aetiology the priority may be an accurate list of all incident cases in the birth cohort and their history of exposure. Local and national priorities also conflict.

Studies of registers are unanimous in emphasising the need for comparability.^{2 10 15 16} But effective coordination is lacking among and between the district health authorities currently developing SCRs, the social service departments currently setting up registers of disabled children, and the general practitioners currently computerising their practice registers (80% by

April 1991).¹⁷ A national policy on health information systems for children with special needs is urgently needed. Without this the potential contribution to continuity of care for individual children, to planning and monitoring services at regional and national level, and to facilitating research in the aetiology and treatment of uncommon conditions will be lost.

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Chronic neutropenia

Experience in Texas (OG Jonsson and GR Buchanan, *American Journal of Diseases of Children* 1991; 145: 232-5) confirms that chronic neutropenia in children is usually fairly benign. Fifty cases of chronic neutropenia (neutrophil count less than $1.5 \times 10^9/l$ for more than eight weeks) were seen in a regional referral centre over a period of 13 years. Three children had congenital neutropenia and two siblings had cyclical neutropenia, one of whom died of staphylococcal septicaemia. Two other patients had severe disease, one of whom died of sepsis and the other was severely ill with massive lymphadenopathy, hepatosplenomegaly, and mouth ulcers but recovered after three years on treatment with cyclosporin.

The remaining 43 patients had a relatively benign course with frequent but usually mild infections of the upper respiratory tract, ears, and skin. Mild splenomegaly was noted in six and 80% of the children were younger than 2 years at the onset. Six of 23 girls had at some time an abscess or cellulitis involving the labia majora and in three the infecting organism was *Pseudomonas aeruginosa*.

Follow up information was available for 36 of the 43 children with benign disease. The white cell count had returned to normal in 23 of them after a median duration of 19 months. Thirteen were still neutropenic after a median interval of 18 months.

Chronic idiopathic neutropenia in childhood is uncommon. It usually runs a fairly benign course with mild infections responding well to antibiotic treatment and no need for antibiotic prophylaxis. Labial infection especially with pseudomonas may suggest this condition.

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