Does the Child Health Computing System adequately identify children with cerebral palsy?

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Abstract

Background This paper assesses the usefulness of the Child Health Computing System as a source of information about children with cerebral palsy.

Methods A comparative survey of information held on the Child Health Computing System (CHCS) and the Northern Ireland Cerebral Palsy Register (NICPR) in one Health and Social Services Board in Northern Ireland was carried out. The sample comprised children with cerebral palsy aged 5–9 years.

Results Of the 135 cases recorded on the NICPR, 47 per cent were not found on the CHCS; the majority of these children had no computer record of any medical diagnosis. Of the 82 cases recorded on the CHCS, 10 (12 per cent) were not found on the NICPR; five of these cases (6 per cent) were found on follow-up not to have CP.

Conclusions Unless improvements are made in case ascertainment, case validation and recording activities, the evidence suggests that the CHCS will not be able to provide the same quality of information for needs assessment and surveillance of very low birthweight infants in relation to cerebral palsy as is provided by a specialist case register.

Keywords: cerebral palsy, needs assessment, child health surveillance, child health computing

Introduction

The Child Health Computing System (CHCS) was designed to provide 'a comprehensive record system which will suit the needs of clinicians, epidemiologists, statisticians, and managers within the NHS'. There is some evidence that the CHCS has improved immunization uptake in parts of the United Kingdom. However, other reports suggest the CHCS may be cumbersome, and contain incorrect and missing data and discrepancies when compared with other routine data sources. The extent to which the CHCS has been able to supply accurate and timely information about the numbers of children with special needs remains unclear. In this paper we assess the usefulness of the CHCS as a source of information on the numbers of children with cerebral palsy.

Method

The Northern Ireland Cerebral Palsy Register (NICPR) was set up in 1991 and includes information on children born since 1977. Multiple sources of case ascertainment are used, including paediatricians, neonatologists, senior or clinical medical officers, orthopaedic surgeons, paediatric physiotherapists and parents. Possible cases are notified to the Register. Before they are included on the Register as confirmed cases, each is followed up with a standardized assessment form, reported elsewhere. The assessment form is usually completed by the notifying doctor. It is then reviewed by the paediatrician of the NICPR. The age of confirmation of diagnosis is five years.

The origins of the CHCS have been described elsewhere. In Northern Ireland the CHCS was initiated in 1986 and has been implemented in different stages across the four Health and Social Services Boards. The system comprises five modules including a field for medical diagnosis as part of the core dataset.

A comparison of the NICPR and CHCS was undertaken in one Health and Social Services Board for all children born 1986–1990, i.e. aged 5–9 at the time of the study in July 1995. There were 53,363 livebirths in the Board during this period. The CHCS was searched using ICD9 codes: 343.0–343.9 ('Infantile Cerebral Palsy Syndromes') and 333.7 ('Aethetoid or Vogt's Disease').

Results

A total of 145 cases of cerebral palsy were recorded between the two systems: 135 cases were recorded on the NICPR and 82 cases on the CHCS. Half of all cases (72/145) were recorded on both systems.

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Of the cases recorded on the NICPR, 47 per cent (63/135) were not found on the CHCS. However, 8/63 cases remained unconfirmed cases on the NICPR (i.e. awaiting completion of assessment forms). Using the CHCS to follow up the remaining 55 confirmed cases revealed that: no medical condition was recorded in 28/55 (51 per cent); an alternative medical diagnosis such as epilepsy, learning difficulties, or hydrocephalus was recorded in 19/55 (34 per cent); coding errors or inconsistencies such as alphanumeric entries or use of categories of motor impairment outside the infantile cerebral palsy syndromes were encountered in 7/55 (13 per cent); and incorrect child details in 1/55 (2 per cent) of cases.

Of those cases recorded on the CHCS, 12 per cent (10/82) were not known to the NICPR. On follow-up, five of these cases did not have cerebral palsy, i.e. 5/82 (6 per cent) were false positives.

Discussion and conclusion

We have identified incompleteness and inaccuracy in the CHCS data relating to children with cerebral palsy. We do not know the extent to which this is generalizable to other areas in the United Kingdom but our results emphasize the importance of verifying the quality of data held. Disease registers can be useful in such an audit. Although the NICPR is not a 'gold standard', its reported prevalence rate of 2.2 per 1000 (confidence interval 1.9–2.5) for the 5–17 age group is comparable with that of other CP registers.8

It was originally hoped that the CHCS should be able to replace disease-specific registers for children, and in Northern Ireland the Cerebral Palsy Register was viewed by many community medical officers as unnecessary when all the modules of the CHCS had been implemented. Theoretically, we believe the CHCS can replace a register, but only if the CHCS incorporates the active case ascertainment and validation activities of a register.

In a health service context the CHCS–Register has two aims. First, the system must be able to provide information about the number of children with particular special needs in the community. It could be argued that the diagnosis is not necessary, provided special needs are recorded. However, the recording of need can be more subjective than the diagnosis which generates it. Thus for any more sophisticated analysis of temporal or geographic differences, or socio-economic inequalities, all important to the needs assessment process, a multifaceted description including diagnosis, severity and associated impairments is most useful. It could also be argued that an estimate of numbers from the epidemiological literature (such as 2 per 1000 births) is as good as counting the relatively small variations between communities. This is certainly better than relying on an incomplete information system. However, from a service delivery point of view it may be necessary to know which children are affected and from a community point of view there may be a demand for health service and risk factor evaluation that requires children to be identified for an analysis to be carried out. Second, the information system must be able to assess any changes in the prevalence of cerebral palsy in relation to its major risk factors. The major issue here is the high prevalence of cerebral palsy among very low birthweight survivors.9 We must be in a position to see whether the prevalence is rising or falling among very low birthweight survivors, and the severity of the condition among survivors, to evaluate changes in neonatal care and to prepare health, social and educational services to cater for these children and their families.

How can these two aims be achieved? High case ascertainment and a high level of standardization of definitions and classifications are essential, because cerebral palsy is difficult to define, varies by type, severity, aetiology and pathology, and its presentation may change,10 and can only be achieved by an active process of validation, whoever undertakes this. Each health authority must be clear about what it is expecting from its CHCS and whether mechanisms are in place to achieve this. If an external register is supported, then the CHCS can play an important role as notifier and supplier of information such as birthweight and denominator data, and the register can in turn feed back into the CHCS. Registers can also have added value as the focus of health service and aetiological research.

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References

5 Morris RW, Lakhani AD, Morgan M, Dale C, Vaile MSB. The role of information flow between health professionals and the Child Health Computer System in the uptake of


8 Paneth N, Kiely J. The frequency of cerebral palsy: a review of population studies in industrialised nations since 1950.


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