

Validation of the reporting bases of the orthopaedic and paediatric surveillance schemes

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Abstract

Background—Nationally representative estimates of treatment rates for congenital dislocation of the hip were required to inform a review of the current United Kingdom screening policy. Cases were ascertained through an active reporting scheme involving orthopaedic surgeons and the existing British Paediatric Association Surveillance Unit (BPASU) scheme.

Objective—To report the methods used to establish, maintain, and validate the orthopaedic and BPASU schemes.

Methods—Multiple sources were used to develop the orthopaedic reporting base. Surgeons treating children were identified by postal questionnaire. The orthopaedic and paediatric reporting bases were compared to the 1992 manpower census surveys of surgeons and paediatricians.

Results—A single source of respondent ascertainment would have missed 12% of the 517 surgeons who treated children. Comparison with the manpower census data suggests the orthopaedic and paediatric reporting bases were 97% and 92% complete.

Conclusions—Multiple sources should be used to establish and maintain a reporting base. Targeting respondents avoids unnecessary contact, saves resources, and may improve compliance. Manpower census data can be used for regular validation of the reporting base.

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In 1969, universal screening for congenital dislocation of the hip (CDH) was formally introduced in the United Kingdom¹ in order to detect and treat at an early stage infants who would otherwise develop established hip dislocation. The extent to which this screening programme achieves its objective is controversial,²⁻⁵ and in view of this, an MRC working party was established, at the request of the Department of Health,⁶ to review the current national screening policy. As part of this review, a study was initiated to obtain nationally representative estimates of rates of treatment with abduction splinting and operative procedures for CDH in children aged 5 years and under.

As appropriate routine national sources of data for CDH are lacking,⁷ cases were ascertained through active reporting by consultant

paediatricians and consultant orthopaedic surgeons. Reports from the former were obtained through the British Paediatric Association Surveillance Unit (BPASU) reporting scheme, established in 1985 for the surveillance of rare childhood conditions that could not be monitored through existing data collection systems.⁸ Paediatricians in Britain and Ireland are asked to report cases of a number of specific conditions (usually 12) seen in the preceding month on a monthly postcard, and a 90% card return rate has been reported.⁸ As the BPASU scheme has been used previously to determine the incidence of more common conditions such as diabetes,⁹ it was considered appropriate for estimating treatment rates for CDH. However, to minimise the burden of reporting for clinicians, a relatively short reporting period was chosen. Since orthopaedic surgeons treat CDH, and both consultant paediatricians and surgeons treat hip instability,^{2, 10} a parallel orthopaedic surveillance (OS) scheme was established. This paper reports the methods used to establish and maintain the OS scheme, and the results of a study to validate the reporting bases of the BPASU and OS schemes.

Methods

DEVELOPMENT AND MAINTENANCE OF THE ORTHOPAEDIC REPORTING BASE

In January 1993, a list of consultant orthopaedic surgeons currently practising in the United Kingdom was collated from the British Orthopaedic Association (BOA) and the British Society of Children's Orthopaedic Surgery. Surgeons were initially sent details of the study and were requested to complete and return a form indicating whether they ever treated children. A reminder letter and second form were sent after three weeks, and the secretaries of non-respondents telephoned after a further two weeks. Surgeons who treated children were eligible for inclusion in the surveillance scheme and surgeons were included if there was doubt about their eligibility. If the information was not volunteered, secretaries were asked to name any orthopaedic consultant in the department specialising in the treatment of children. New surgeons thus identified were added to the reporting base. All requests for information throughout the study could be sent to a FREEPOST address.

The reporting base was updated throughout the study period from information regarding recent consultant appointments provided by the BOA, and by monitoring advertisements for consultant orthopaedic posts in the *British*

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BPSU/BOA REPORT CARD		April 1993 [83]
		Code no. [12345]
<input type="checkbox"/>	Please tick if NO CASES TO REPORT	
<input type="checkbox"/>	number of cases of ABDUCTION SPLINTING	
<input type="checkbox"/>	number of cases of a FIRST OPERATIVE PROCEDURE	
<p>Please report 1) The number of infants or children with CDH in whom treatment with abduction splinting was started in the last month. 2) The number of children with CDH aged 5 and under receiving a first operative procedure for CDH with or without general anaesthesia in the last month.</p>		
PLEASE RETURN THIS CARD EVEN IF YOU HAVE NOTHING TO REPORT		

Figure 1 Monthly reporting card for orthopaedic surgeons.

Medical Journal and the *Lancet*. For each consultant post advertised, the relevant personnel department was contacted to ascertain whether the job description included a paediatric workload. Successful candidates for posts with an anticipated paediatric workload were subsequently contacted with details of the study and reporting scheme, and asked whether they were responsible for treating children with CDH. Those eligible were added to the reporting base and asked to report any children treated at any time during the study period. Surgeons were removed from the reporting base if retirement, sickness, or death occurred during the study period, or if they subsequently informed the study coordinator that they did not treat children with hip instability or CDH.

DEVELOPMENT AND MAINTENANCE OF THE PAEDIATRIC REPORTING BASE

The BPASU scheme has been described previously.⁸ The reporting base comprises members of the British Paediatric Association and members of the Faculty of Paediatrics of the Royal College of Physicians in Ireland. Paediatricians are withdrawn from the reporting base on request or, as for the OS scheme, owing to retirement, sickness, or death.

SURVEILLANCE METHODS

At the end of each month, from April 1993 to April 1994 inclusive, surgeons were sent an OS reporting card, and asked to complete and return one half, indicating the number of children under their care receiving a first operative procedure for CDH in the preceding month, or that they had nothing to report (fig 1). The remaining portion was designed to allow the reporting surgeon to record identifying details of any children notified that month. A copy of the study protocol was included in the first month's mailing. In addition, both surgeons and paediatricians were asked to notify all children treated with abduction splinting for the months April to July 1993 inclusive, the latter on the BPASU card. A one page form request-

ing further details of the child was sent for each case reported. Special reporting arrangements were made for some surgeons with a high CDH case load. These included providing forms in advance, and arranging for a nominated person such as an orthopaedic nurse or physiotherapist to report cases and complete forms on their behalf. In some centres duplicate reporting was minimised by either an orthopaedic surgeon or a paediatrician undertaking to report all cases for that centre.

Monthly reminders were sent to surgeons not returning OS reporting cards, offering a further opportunity to state whether children with CDH were not treated. The BPASU scheme usually sends reminders to only those paediatricians with three consecutive cards outstanding but, for this study, a reminder requesting notification of children treated with abduction splinting was sent to paediatricians with one or more outstanding cards for April to July 1993. Surgeons received progress reports twice during the study period and, if appropriate, were prompted for outstanding cards and follow up forms. Regular feedback to paediatricians was provided through the BPASU quarterly bulletin.

All data were entered with a double entry system (Epi-info v.6, Atlanta). 'Smart' software (Innovative Software, 1986) was used for the databases and to track the return of cards. Data were transferred electronically between the BPASU office and the study coordinators between April and July 1993, but subsequently the latter coordinated the mailing of the orthopaedic reporting cards and data entry.

VALIDATION OF THE ORTHOPAEDIC AND PAEDIATRIC REPORTING BASES

The OS and BPASU reporting bases were compared with lists of consultants compiled independently as part of the United Kingdom orthopaedic and paediatric manpower censuses carried out in September 1992. Details of the surname, initials, hospital, health district, and region of each surgeon and paediatrician listed in the manpower census data set were

Table 1 Source from which surgeons were identified for inclusion in the orthopaedic surveillance scheme

Source	No	No who treat children with CDH
Home Fellow* of the BOA† in January 1993 with a current UK address	1086	453
Nominations from other surgeons, and successors of retiring surgeons	9	7
New Home Fellows	79	25
Surgeons identified by secretaries during telephoning	7	7
Opportunistically	4	4
New appointments advertised in <i>British Medical Journal</i> and <i>Lancet</i>	40	21
Total (%)	1225 (100)	517 (42)

* Home Fellow: consultant orthopaedic surgeon practising in the UK.

† British Orthopaedic Association.

provided as a comma delimited ASCII file. The initial cross reference was made on the basis of surname. Records with duplicate surnames were checked by hand and matched by initials.

Consultant orthopaedic surgeons and paediatricians identified from the manpower censuses, but not included in the respective surveillance schemes, were sent a questionnaire to establish whether they had been a consultant at any point during the study period, whether this had been at the institution listed in the manpower census, and whether they had treated children for hip instability or CDH during this period. In addition, paediatricians were asked to identify any special interests.

Results

TARGETING OF ORTHOPAEDIC SURGEONS

The initial questionnaire was returned by 749 surgeons (69%) within three weeks of the first mailing. A total of 82% had replied two weeks after the postal reminder, leaving 194 non-

respondents whose secretaries were telephoned. Of the 1225 surgeons identified, 517 (42%) indicated that they treated children and were thus included in the OS scheme. The number of orthopaedic consultants identified through the various sources and the number who treat CDH are given in table 1.

CARD RETURN RATE

Direct comparison of card return rates between the OS and BPASU schemes was possible for the period April to June 1993 only, when the published card return rate for paediatricians was 91%¹¹ and the corresponding figure for surgeons was 83%. The reminder to paediatricians for cases of CDH increased the percentage of returned cards to 96%.

When examined by country or former NHS region, the OS scheme card return rate showed marked variation (fig 2), ranging from 70% for the Northern region to 91% for the Mersey region. Variation in the BPASU card return rate¹¹ was less marked, ranging from 88% for North East Thames to 100% for Northern Ireland. There was no apparent concordance in the geographical variation in card return rates between the two schemes (fig 2). (Wilcoxon matched pairs signed ranks test, $p < 0.001$.)

COMPLETENESS OF THE ORTHOPAEDIC REPORTING BASE

The orthopaedic manpower census identified 1047 current consultant posts, of which four were vacant. Of the 60 surgeons named in the manpower census but not included in the OS scheme, seven did not reply to the postal questionnaire, 32 were consultant orthopaedic surgeons but had not treated children with CDH, and four were not consultant orthopaedic surgeons in clinical practice in the United Kingdom during the study period. This suggested that only 3% (17) of surgeons responsible for treating children for CDH were not included in the OS scheme.

COMPLETENESS OF THE PAEDIATRIC REPORTING BASE

The paediatric manpower census identified 1130 current consultant posts, of which 909 were hospital based, 221 community based, one both, and 61 either vacant or occupied by a locum. Of the 129 paediatricians listed in the manpower census but not included in the BPASU scheme, 17 did not return the postal questionnaire and 14 were not in clinical practice in the United Kingdom during the study period. Three of the six paediatricians who

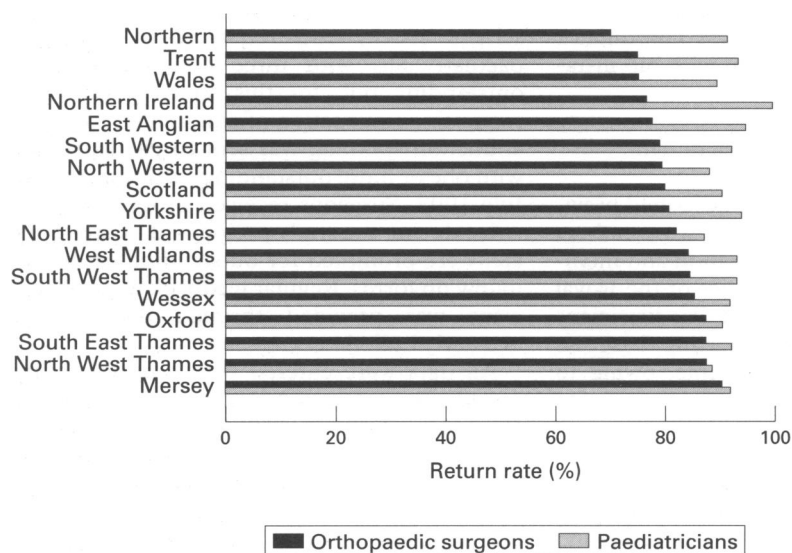


Figure 2 Variation in orthopaedic surveillance (OS) scheme and British Paediatric Association Surveillance Unit (BPASU) card return rate by country and region.

Table 2 Reported special interest(s) of paediatricians not in the BPASU

Special interest(s)	No of paediatricians (%)
Community child health or neurodevelopment*	40 (41)
Other†	27 (28)
Neonatology	23 (24)
None/not specified	8 (8)

* Includes special needs assessment, child abuse.

† Includes subspecialties such as respiratory medicine, oncology, endocrinology, immunology, infectious disease, gastroenterology, intensive care.

reported that they had initiated treatment for hip instability during the study period specified that such children had been referred to an orthopaedic surgeon, who was included in the OS scheme. Of the paediatricians not included in the BPASU, 41% reported a special interest in community child health or neurodevelopmental assessment, and 24% in neonatology (table 2).

Discussion

A surveillance scheme may be established to monitor the frequency of specific disorders in order to detect the early stages of an epidemic; to monitor the effectiveness of an intervention; to identify rare disorders for more detailed study; or to establish the prevalence of a condition. With the demise of regional health authorities and the reduction in the extent of routine health services data collection, voluntary surveillance schemes may assume greater importance.

There has been considerable interest internationally in the BPASU reporting scheme as a method for determining the incidence and prevalence of rare and common disorders of childhood, and several countries, including The Netherlands and Australia, have established similar schemes.¹¹ Since specialists other than paediatricians are frequently involved in the diagnosis and treatment of childhood conditions, parallel reporting schemes involving other clinicians and laboratory staff have been established including obstetricians and gynaecologists for HIV surveillance,¹² neurologists for subacute sclerosing panencephalitis,¹¹ ophthalmic surgeons for congenital cataract,¹¹ and laboratories for *Haemophilus influenzae* b.¹¹ In addition, dermatologists, pathologists, and rheumatologists have been included on a temporary basis in the BPASU scheme.

A key feature of the BPASU scheme is that it allows a coordinated approach⁸ to the surveillance of several conditions by using a single reporting card, thereby avoiding multiple contacts with paediatricians and minimising their reporting workload. It is also cost effective to resource one system which facilitates research into several conditions. In contrast, the OS scheme included only a single condition, was of limited duration, and targeted only those surgeons who ever treat children.

One measure of compliance with a scheme is the proportion of reporting cards returned. This is sometimes described as the *response rate*, but should perhaps be more accurately termed the *card return rate*, since a completed card does not guarantee a complete response in terms of the cases ascertained. The OS scheme card return rate was good, and although not as high as that for the BPASU, was higher than that of the dermatologists, pathologists and rheumatologists reporting to the BPASU, who achieved rates of 62%, 63%, and 63% respectively.¹¹ This suggests that it is possible to achieve good compliance with a reporting scheme in a relatively short period (less than

three months preparation) among specialists with no prior experience of an active reporting scheme.

The initial questionnaire employed in the OS scheme allowed 708 surgeons who never treat children to be excluded. Avoiding unnecessary contact with clinicians who never treat children saved resources and potentially improved compliance. The effect of including in a surveillance scheme those clinicians who never, or only rarely, see a child with a notifiable condition may be in two directions: clinicians may have little interest in the study and neglect to make nil returns; alternatively, they may be motivated to participate, without the disincentive of requests for further information consequent on reporting a case. The former may reduce, and the latter inflate, apparent compliance without affecting case ascertainment. In either case, the card return rate may be a misleading measure of the success of the reporting scheme. Further, while it is possible to calculate the proportion of participating clinicians who make a monthly return, there remains the question of how many treating clinicians have not been included in the scheme.

Recently, attention has been focused on capture-recapture analysis,¹³ a method developed to estimate the size of animal populations. This technique relies on case ascertainment from two or more independent sources and uses the proportion of cases found in common with other sources to estimate the total number of cases. Where multiple independent sources of cases are not available and the approach is not feasible for the condition, the completeness of a single source of data, such as the BPASU reporting scheme, assumes greater importance. If, at the outset, membership of the OS scheme had included only members of the largest professional organisation, the BOA, 12% of relevant surgeons would have been missed. Comparison with the manpower census data suggested that by using multiple sources of respondent ascertainment and monitoring new appointments, only 3% of surgeons had not been included in the OS reporting base. For the BPASU, the coverage of the reporting base appeared to be lower, with 8% of eligible paediatricians not included in the BPASU. This may reflect differences between the schemes in the methods used to compile and maintain the reporting base. Although only a small percentage of these paediatricians treated children with CDH, the impact of this underascertainment in the BPASU scheme may be more pronounced for other conditions, particularly those seen by community paediatricians, neurologists, or neonatologists.

The complete accuracy of any reporting scheme is not a realistic expectation. There will be imperfections of the data, but with careful monitoring of the scheme it should be possible to give at least qualitative details of these, and perhaps estimate the extent of the problem. This is essential information to provide a setting for any study findings. Details of the methods of data collection and data quality are essential to provide an informed perspective

with which to view the results of a study. Multiple sources should be used to establish and maintain a complete reporting base, while respondents should be targeted if possible to avoid unnecessary workload for clinicians and save resources. Manpower census data are a potentially useful means of periodic validation for the BPASU and similar United Kingdom schemes.

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- 1 Standing Medical Advisory Committee. *Screening for the detection of congenital dislocation of the hip in infants*. London: Department of Health and Social Security, 1969.
- 2 Clarke NMP. Diagnosing congenital dislocation of the hip. *BMJ* 1992;305:435.
- 3 Dunn PM. Diagnosing congenital dislocation of the hip. *BMJ* 1992;305:885.
- 4 Bennet GC. Screening for congenital dislocation of the hip. *J Bone Joint Surg (Br)* 1992;74-B:643-4.
- 5 Watson JAS. Screening for congenital dislocation of the hip. *Matern Child Health* 1990;15:310-4.
- 6 Dezateux C, Godward S. Evaluating the national screening programme for congenital dislocation of the hip. *J Med Screening* 1995;2:200-6.
- 7 Macfarlane A. Congenital dislocation of the hip—an epidemiological conundrum. *J Matern Child Health* 1980; 13-15.
- 8 Hall SM, Glickman M. The British Paediatric Surveillance Unit. *Arch Dis Child* 1988;63:344-6.
- 9 Wadsworth E, Shield J, Hunt L, Baum D. Insulin dependent diabetes in children under 5: incidence and ascertainment validation for 1992. *BMJ* 1995;310:700-3.
- 10 Dunn PM, Evans RE, Thearle MJ, Griffiths HED, Witherow PJ. Congenital dislocation of the hip: early and late diagnosis and management compared. *Arch Dis Child* 1985;60:407-14.
- 11 British Paediatric Surveillance Unit. *Eighth annual report, 1993*. British Paediatric Surveillance Unit, 5 St Andrews Place, Regent's Park, London NW1 4LB, 1994.
- 12 Davison CF, Holland FJ, Newell ML, Hudson CN, Peckham CS. Screening for HIV infection in pregnancy. *Aids Care* 1993;5:135-40.
- 13 Laporte RE. Assessing the human condition: capture-recapture techniques. *BMJ* 1994;308:5-6.