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Editorials

Registration of blind and partially sighted people

Two important papers appear in this issue which are linked by the registration process for blind and partially sighted people in the UK. Fielder's group has investigated the extent to which persons eligible for registration seen in the hospital eye service actually get registered and the reasons for non-registration. Clark and colleagues, from Bristol, have looked for explanations for the blindness of diabetic patients from retinopathy, a condition (in theory at least) entirely preventable, and used the registration of these patients as a way of identifying them.

The Birmingham study underlines the conclusions of the Royal National Institute for the Blind's (RNIB) Needs Survey¹ and the Royal College of Ophthalmologists² recent reminders on the importance of the certification process in facilitating access to social services support for visually (and often multiply) disabled people. The authors find an under-certification rate which is less than that found by the RNIB although this can be explained by the fact that the latter was community based (at least in part) while the Birmingham study is hospital based. Other studies have shown that a third or more of visually impaired people in the community have never seen an eye specialist.³ Relevant to the Bristol paper is that less than half the patients in Birmingham eligible for certification because of diabetic retinopathy were actually certified.

It is an appropriate time to review the blind and partial sight registers and especially to consider experience gained since the change in the system in 1990 and introduction of the new BD8 form. The impetus behind the reform of the registration system was to solve two problems: firstly, there was concern about the ethics of passing confidential clinical information on a standard form to non-medical personnel in local authorities⁴; secondly, an ever decreasing proportion of BD8 forms were being passed on from the local authorities to the Department of Health for analysis. The new system whereby anonymous epidemiological data (part 5 of the BD8 form) are separated from the certificate of blindness (parts 1-4) and sent directly to the Office of Population Censuses and Surveys (OPCS) has successfully addressed both problems. Part 5 is coded by OPCS and the data for the first year of the new system April 1990 to March 1991, comprising over 30 000 records, form a unique database - the Blind and Partial Sight Survey (BPSS) - which is available to medical researchers. This has had the effect, perhaps not anticipated by the Department of Health, that for the first time the validity of the epidemiological data collected during the course of registration for blindness and partial sight can be assessed.

Apart from the problems of coverage which have always been of concern with the register,⁵ problems have been identified with the BD8 form mainly as a result of ambiguities as to how the form should be completed compounded by coding errors when the forms are coded, albeit by highly experienced coders but unsupported by ophthalmic expertise. This issue is discussed in more depth in a previous paper which showed that for an important cause such as diabetic retinopathy, up to 50% misclassification can occur.⁶ Should the figures for 1990 show a dramatic fall in the proportion of new certifications due to diabetic retinopathy, it is possible that it could be entirely explained by this misclassification.

One method of avoiding this type of coding error is to facilitate coding by ophthalmologists at source. The specification for a computer based coding system which ophthalmologists could use at the time of certification for completion of the form and selection of an appropriate Read code for cause (or causes) is currently being developed. This program will be evaluated and tested over the next year before development of a final specification which could be incorporated in clinical database management systems.

The Department of Health does not undertake to analyse BD8 forms for all age groups more often than every 10 years, although simple analysis of statistics for children occurs every year. Some doubt now exists among ophthalmologists as to the value of completing part 5, given that it is so infrequently analysed and apparently so unreliable.

The Bristol paper highlights one reason why it might be important to collect these data. The paper uses the local register to identify diabetics who have been blinded by their retinopathy in order to investigate how the system failed to prevent this avoidable sight loss. One of the St Vincent Declaration targets was the reduction of new blindness due to diabetes by one third or more over 5 years.⁷ Although data collected specifically for this purpose may be available for comparison within Europe on a sample of diabetics, the BPSS, were it to be of adequate reliability, would offer an excellent way to assess whether such targets are met at a national level.⁸ This also applies to other important causes of avoidable visual loss including retinopathy of prematurity and glaucoma.

The BPSS could also be useful for monitoring trends in diseases generally not amenable to treatment. Analysis of available data over the past 40 years suggests that there has been a doubling in (age-standardised) annual registration for aging maculopathy but we cannot be sure if this increase is real or artefactual because of uncertainties over diagnostic drift and possible changes in the threshold at which people

are registered.⁹ Is it not vital that we do know what is happening and that reliable information is available on the main causes of irremediable visual loss afflicting our community? If so, it is up to our profession to ensure that such data are collected and their quality improved.

A major problem with the register is its dual function, as pointed out by Brennan and Knox,⁴ primarily as a mechanism of coordinating support for visually disabled people but with a subsidiary epidemiological role. These two functions have quite different requirements. A strict definition of visual impairment is probably a hindrance for the identification of individuals in need of support because there are wide variations in need in relation to a single level of measured impairment. It is a serious flaw in the epidemiological value of the BPSS that there is no record of the level of visual loss on the form returned to OPCS. As a result, it will be difficult to distinguish between real changes in incidence and those changes occurring because of the drift in the threshold at which people are registered. This may account for some of the observed increase in registration for aging maculopathy but we now have no means of taking this into account.

There are potential solutions to these problems which may be effected with the minimum of change to the system as it stands. There is no definition of partial sight for the purposes of certification (although some recommendations are made). Partial sight certification could therefore be used as the catchall for those in need of social service support. Full registration as blind (and if only this name was changed at the time of reform to severe visual impairment) could be reserved for a much more strict definition (<3/60 in the better seeing eye with additional field criteria which is the WHO definition) for which part 5 could be returned to OPCS.

The Birmingham study shows us that a not large but significant group of individuals decline the offer of certification because they do not wish to be the recipients of charity or in some other way fear or resent the associated stigma. Because part 5 is entirely separate and anonymous, there is no reason why it should not be completed on its own when a

patient does not wish to be registered. Thus, ophthalmologists would report every case of irremediably lost vision (to the defined level) by the standardised coding procedure for cause. Were we able to achieve this, we would have a system which could provide both surveillance and monitoring of time trends for irremediable visual loss in our community which we believe would be invaluable both for the purposes of research and audit.

Before such changes could be implemented, however, the appropriate authorities would need to have a genuine debate (preferably supported by systematic research) about the future of the epidemiological data on the register. It is up to ophthalmologists, as collectors and users of this information, to play an active role in decisions as to whether or not this process is worthwhile. There is now an opportunity to build on the positive changes made in 1990 and take the next step to improve these data. If it is worth collecting information of this sort at all, it is worth doing it properly.

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- 2 Royal College of Ophthalmologists. *Registration and rehabilitation of the blind*. London, 1993.
- 3 Cullinan TR. Epidemiology of visual disability. *Trans Ophthalmol Soc UK* 1978; 98: 267-9.
- 4 Department of Health. *Coordinating services for visually handicapped people: report to the minister for the disabled*. London: HMSO, 1989.
- 5 Brennan ME, Knox EG. An investigation into the purposes, accuracy, and effective uses of the Blind Register in England. *Br J Prev Soc Med* 1973; 27: 154-9.
- 6 Evans JR, Wormald RPL. Epidemiological function of BD8 certification. *Eye* 1994; 7: 172-9.
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- 8 Evans JR, Wormald RPL. Monitoring blindness from diabetic eye disease. Paper presented at the Third Meeting of the European Association for the Study of Diabetic Eye Complications. *EASDEC* 1993: 4-6 April 1993 (abstract).
- 9 Evans JR, Wormald RPL. Is the incidence of registrable age-related macular degeneration increasing? *Invest Ophthalmol Vis Sci* 1994; 35: 2003 (abstract).