EPIDEMIOLOGICAL FUNCTION OF BD8 CERTIFICATION

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SUMMARY

The quality of information collected during certification for blindness and partial sight was assessed using a combination of review of the literature on registration and analysis of 17 695 BD8 certificates received by the Office of Population Censuses and Surveys (OPCS) between June and November 1990. Three problems were identified which affect the epidemiological function of these data: interpretation of the definitions of blindness and partial sight has changed over time; the degree of under-certification is unknown (although it could be as high as 64% for blind and 77% for partially sighted people); and the cause of visual disability recorded by the ophthalmologist may not always be adequately transmitted into the statistical analyses. Guidelines for completion of part 5 of the BD8 form need to be developed. Strategies for improving the quality of these data are discussed.

In common with many other industrialised countries, Britain lacks information on prevalence and incidence of common eye diseases.[1] Data collection at the population level is time-consuming and expensive. It is very rare that individual investigators will have the time and resources to monitor whole populations over time. Thus epidemiologists have often made use, opportunistically, of data collected for other administrative purposes. Such routine data can be available for entire populations and over long periods; mortality data, for example, have been analysed by cause for three centuries.

The number of blind people in Britain has been counted since 1851, starting with a simple declaration of blindness on census returns. These were discontinued after 1911 but, after the Blind Persons Act 1920, with its statutory advantages to the registered blind (such as a pension on reaching the age of 50 and domiciliary assistance), a register of blind persons was instituted. Initially all that was required for registration was a certificate from any medical practitioner that the patient was blind. Registration became more stringent with time, however, and from the mid 1930s certificates were accepted only on designated forms (BD8) when signed by ophthalmologists. In 1955 the consultant ophthalmologist became the person responsible for registration.

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The National Assistance Act 1948 set up the current system of registration, with local authorities empowered to establish registers of people with disabilities, including those blind and partially sighted, and to administer the statutory services to which the blind are entitled. Registration was introduced as a social and legal instrument to determine how the community should deal with particular individuals with visual handicaps. The primary purpose was to coordinate services for visually disabled people.

Prior to 1990, BD8 forms were sent from the consultant ophthalmologist to the Local Authority Social Services department by a variety of routes. In October 1983 the Department of Health (DH) reviewed the arrangements for certification and registration. Among the concerns of this review was the issue of medical confidentiality and the analysis of the epidemiological returns. The DH was only receiving 60% of the anonymised copies required for epidemiological purposes and an increasing proportion were proving difficult to categorise.[2] As a result of this review, the BD8 form was revised and a new form introduced in April 1990 (Fig. 1). Parts 1–4, which contain information relevant to registration, are sent to the local social services office. Part 5, an 'epidemiological return' containing anonymous information on cause, is sent directly to the Office of Population Censuses and Surveys (OPCS) which manages the data on behalf of the DH. The information on part 5 is coded and entered onto computer–the Blind and Partially Sighted Survey (BPSS)–providing for the first time a complete computerised database on cause of visual disability. This has provided a unique opportunity to reassess the data collected. This paper evaluates the quality of these data for epidemiological analysis using a combination of review and reanalysis of published data and analysis of 17 695 BD8 certificates received by OPCS between June and November 1990.

METHODS

Three aspects were considered: definitions of blindness and partial sight; coverage of certification; and accuracy of cause of visual disability recording and coding. Published data and the BPSS database were analysed.

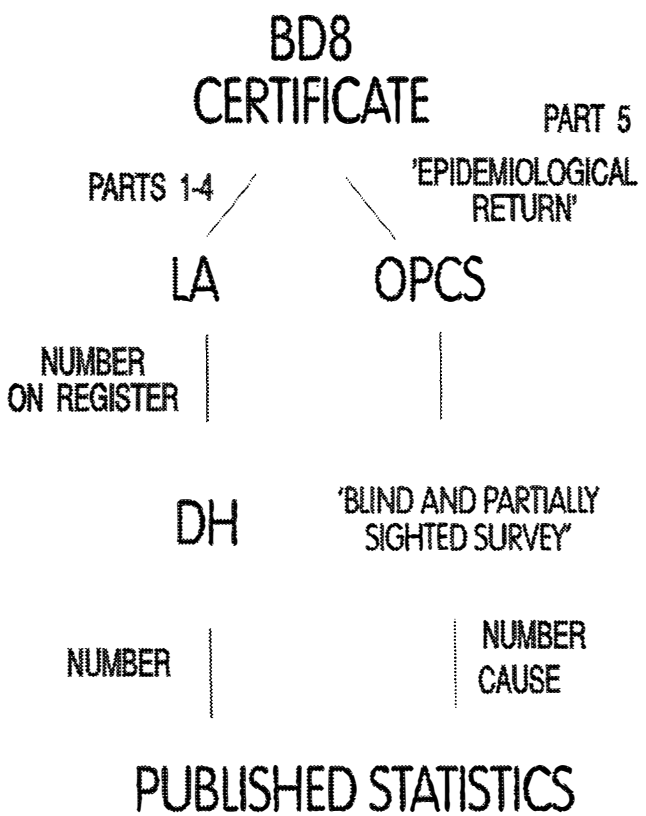


Fig. 1. *Certification and registration after April 1990.*

Comparisons over area and time were standardised by age and/or sex. Standardised registration ratios (SRRs) and standardised certification ratios (SCRs) were calculated by taking the ratio of observed to expected numbers of registrations/certifications in the population subgroup of interest.

SRRs Over Time

Age-standardised registration ratios were calculated from 1976 to 1991 for England only. This time period was selected because data were available for consistent age-groupings. No data by age and sex were available for Wales for this time period. Data on the number of registrations for blindness and partial sight for previous years were taken from tabulations made by the DH.[3] These tables contain information on new registrations by age (0–4, 5–15, 15–64, 65–74, 75+). Data on sex of new registrations in previous years were not available.

Data on registrations were collated by financial year (April–March) whereas the population data used were mid-year estimates.[4,5] The assumption was made that the mid-year estimate of population represented the population at risk from which registrations from April of that year to March of the following year were drawn. Registration data were not available for the following years (i.e. year ending March): 1981, 83, 84, 85, 87, 89 and 90.

SCRs by Region

Out of 17 695 people certified as blind or partially sighted between June and November 1990, 15 328 (86.6%) were classified according to Regional Health Authority (RHA). Data were also missing on age and sex. The SCRs were calculated using standard age–sex specific rates based on all the certificates supplied.

Regional standardised certification ratios were correlated with published data on ophthalmic services and mortality. As there are no reliable regional estimates of morbidity of common causes of blindness and partial sight, mortality data were used as proxy for morbidity.[6] This is less than ideal for two reasons: (1) mortality reflects both incidence and survival; and (2) only a limited number of causes of visual impairment are associated with mortality. Of the causes of blindness with substantial numbers of registrations, only diabetic eye disease and cerebrovascular disease are associated with mortality. Mortality data on diabetes, however, are unreliable with only 20% of associated deaths being coded to this condition, and were not considered here. Regression coefficients were estimated using the SAS computer package.

The BD8 form has 16 fields in which ophthalmic information is recorded. There is one field in which to record the main cause of visual disability (if it can be assessed) (MCAUSE); a further 10 fields for recording ophthalmic conditions leading to visual loss (five for each eye) (A1–A5); and five fields in which to record any diseases causing the specified ophthalmic conditions (B1–B5). The responses are coded according to the International Classification of Diseases (revision 9)[7] and entered onto the computer by OPCS.

The reliability of recording of main cause of visual disability was assessed by analysis of the computerised database derived from 17 695 forms received by OPCS between June and November 1990. The aim was to quantify the reliability with which counts of visual disability by cause could be extracted. Initially the four major causes of registration – ageing maculopathy, glaucoma, cataract and diabetic retinopathy – were examined. Records in which the cause of visual impairment was the same in the right and left eye were selected. For each cause, every record where the cause was coded in any of the 16 fields was selected. Using the information in the MCAUSE, A1 and B1 fields, by cross-tabulation, the records were divided into 'definite' and 'probable'.

Diabetic retinopathy was examined in more depth. All records mentioning diabetes or diabetic retinopathy were selected and divided into the following categories: 'definitely diabetic retinopathy', 'probably diabetic retinopathy', 'possibly diabetic retinopathy' and 'not diabetic retinopathy'. The definitions of these categories are shown in Table IV.

These analyses represent focused exploration of a subsection of the BPSS data and should not be intepreted as official publication of proportion by cause.

RESULTS

The Epidemiology of Registered Blindness and Partial Sight in England and Wales

The number of people on the blind and partially sighted

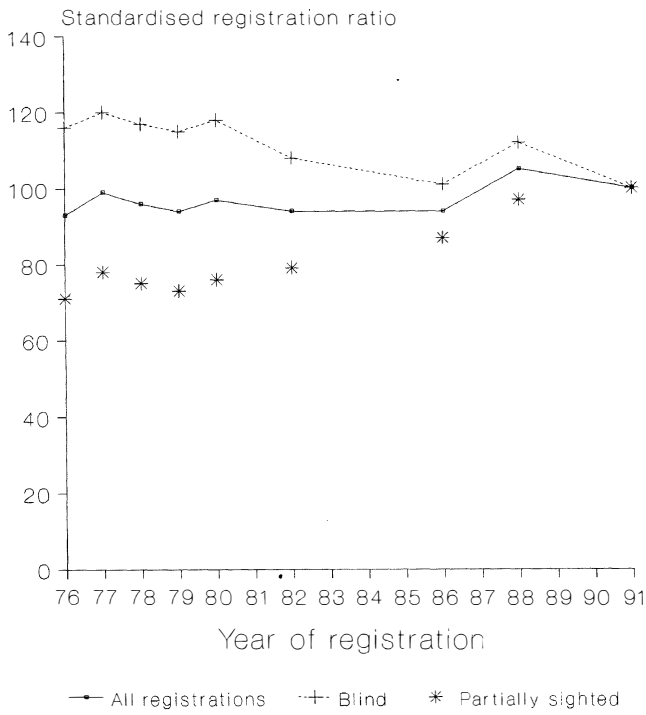


Fig. 2. *Standardised registration ratios by year: England 1976–91. (1991 standard SRR = 100.)*

register in England and Wales at March 1991 was 245 517.[8] Assuming a population at risk of 50 718 762,[9] this gives a prevalence of registered visual disability of 484 per 100 000 population. The number of new registrations in the year ending March 1991 for blindness and partial sight was 29 468, an incidence rate of 58 per 100 000 population. Approximately equal numbers of these registrations were made for blindness and partial sight (14 756 blind, 14 712 partially sighted). Over 84% of the registrations were people over 65 years of age. Approximately equal numbers of males and females were registered in age groups less than 65 years, but for ages 65 and above, over 66% of registrations were female.

The absolute number of new registrations has risen each year. In England, in the year ending March 1976, 17 096 people were registered as blind or partially sighted, almost 40% less than in the year ending March 1991 (27 268). Fig. 2 shows the standardised registration ratios (SRRs) by year from 1976 to 1991 for all registrations and separately for blindness and partial sight in England. Overall, registration has increased to a small extent. Different patterns are observed for blindness and partial sight, however. Registration for blindness has decreased slightly since 1976 whereas registration for partial sight has increased by 30%.

Ageing maculopathy is the commonest cause of registered visual loss. In 1981 (the last year for which cause was analysed for people over 65 years), 5846 (37.0%) of new registrations (aged 16 years and over) were from this cause.[10] This was followed by glaucoma (12.4%), cataract (10.4%), diabetic retinopathy (7.2%) and myopia (4.7%). There has been a considerable shift in cause of registrations since the 1930s, as demonstrated in Table I. Data on partial sight registrations are not available for such a long period so this analysis is restricted to cause of registration for blindness only. Ageing maculopathy accounted for 6% of registrations for blindness between 1933 and 1943,[11] which rose to 15.3% by 1948–50,[12] 21.6% in 1951–4,[13] 26.9% in 1955–60[14] and over 37% in 1981.[13] (Reports between 1962 and 1980/1 only presented data for people less than 65 years of age.)[15] There was a smaller, but steady, increase in the proportion of registrations due to diabetes and vascular diseases. By way of contrast, infectious causes of blindess, for example ophthalmia neonatorum and syphilis, all but disappeared during that time as a cause of registration.

Fig. 3 shows the SCRs by RHA. There was a statistically significant trend of increased certification in RHAs in the north compared with the south.

Fig. 4(a) is a plot of standardised certification ratios (SCRs) by RHA against the standardised mortality ratio (SMR) for all causes for males. There was a positive trend, with regions with high SMRs also having raised SCRs. This trend was highly statistically significant ($p = 0.0004$). A similar trend was observed in females ($p = 0.025$). However, the plot demonstrates that there is a clustering effect and that the regions divide into two groups: regions with low SMRs and low SCRs in the south

Table I. Percentage of people registered as blind by cause in England and Wales between 1933 and 1981

	Year					
					1980–1	
	1933–43 (17 430)[a]	1948–50 (18 150)	1951–4 (30 795)	1955–60 (58 272)	(8949)	(9174)
Cataract	24.6	30.4	26.2	22.6	8.9	8.8
Glaucoma	13.4	14.0	13.6	12.6	12.8	12.5
Myopia	10.8	8.9	8.5	8.8	4.5	4.0
Congenital/hereditary	9.9	7.6	6.8	5.2	3.5	3.4
Syphilis	6.7	1.2	1.0	–	–	–
Ageing maculopathy	6.4	15.3	21.6	26.9	37.7	37.0
Iritis/iridocyclitis	4.7	3.5	2.5	2.3	NA	NA
Optic atrophy	3.5	2.7	2.0	4.2	3.1	3.4
Ophthalmia neonatorum	2.6	–	–	–	–	–
Diabetes		4.3	6.0	7.1[b]	8.0[b]	7.9
Vascular diseases		2.6	3.3	3.9	NA	NA

Data from Sorsby,[11–14] and Government Statistical Service.[10]
[a] Figures in brackets are numbers of certificates.
[b] Diabetic retinopathy only.

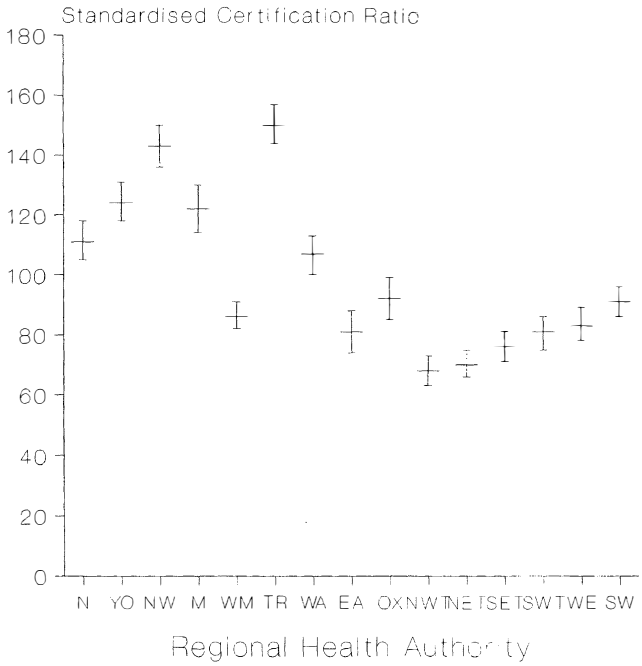


Fig. 3. *Standardised certification ratios by region: England and Wales 1990. Bars indicate 95% confidence limits. (Certifications June–November 1990.) Regional Health Authorities: N, Northern; Yo, Yorkshire; NW, North-Western; M, Mersey; WM, West Midland; TR, Trent; WA, Wales; EA, East Anglian; OX, Oxford; NWT, North West Thames; NET, North East Thames; SET, South East Thames; SWT, South West Thames; WE, Wessex; SW, South Western.*

of the country and regions with high SMRs and high SCRs in the north. After stratification into northern and southern regions, the association largely disappears (Fig. 4b). A similar pattern was observed for females.

For cerebrovascular disease (CVD) there was a strong association between mortality from this condition and SCR in both sexes (Fig. 4c and d) (p = 0.0009 and 0.01 respectively). For every unit increase in SMR there was an increase of 2 units in the SCR. This association remained after controlling for north/south (Fig. 4e and f).

Definitions of Blindness and Partial Sight

Current legal definitions of eligibility for registration as blind or partially sighted are vocational, but the recommendations on the BD8 form as to who should be registered are medical (Table II).

There is little information on how these definitions are interpreted. Prior to 1990, information on visual acuity was published. Table III shows the visual acuity of people registered blind in England and Wales for the years 1933–68. The proportion of registered blind people with perception of light only or less has fallen from 29.8% in 1933 to approximately 15% in 1968, whilst the proportion with better than 3/60 Snellen rose from 4.1% to approximately 30.5% in the same time period.

Table II. Current definitions of registrable blindness and partial sight

Legal definition of blindness
'So blind as to be unable to perform any work for which eyesight is essential'
Which is recommended to be:
Less than 3/60 Snellen in better eye (corrected visual acuity)
Less than 6/60 in better eye with very contracted field of vision
Very contracted field of vision especially in lower part of field
Definition of partial sight
(there is no legal definition)
'Substantially and permanently handicapped by defective vision caused by congenital defect or illness or injury'
3/60 to 6/60 Snellen in better eye with full visual field
Less than 6/24 Snellen with moderate contraction of visual field, opacities in media or aphakia
6/18 or better with gross visual field defects

Accuracy of Cause of Visual Disability Recording and Coding

Table IV shows, for the four major causes of registration, the assessment of the main cause of visual disability coding. For degeneration of the macula and posterior pole (largely ageing maculopathy), examination of information on the rest of the form did not affect materially the main cause analysis. Of 7120 records where the ICD code 3625 'degeneration of the macula and posterior pole' was coded as main cause, 6341 were probably appropriately classified. Of 9039 records where ICD 3625 was coded elsewhere on the record (i.e. not as main cause) 934 would have been more appropriately coded as 3625. In general, the main cause codes for these records were non-specific categories such as visual disturbance (ICD 368–), blindness (369–) or senility (797–). Thus reclassification would only affect the final number produced by 2.2%. Similar findings were seen for glaucoma and cataract, simple tabulation of main cause providing a reasonable count of the numbers certified with these causes.

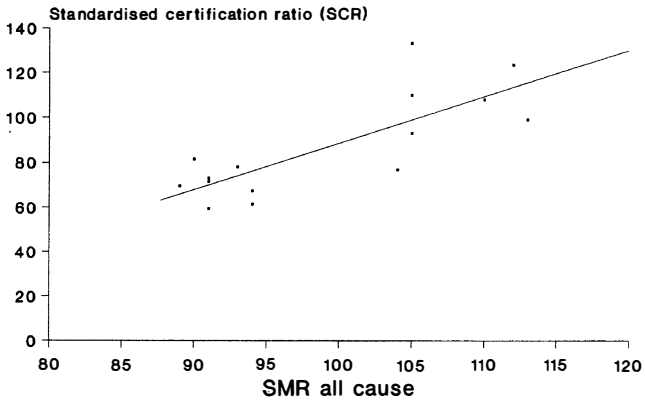
Table V shows the results of the more detailed analysis

Table III. Visual acuity of registrations for blindness in England and Wales 1933–68

Visual acuity at registration for blindness	% of persons registered in:					
	1933–43	1948–50	1951–4	1948–62	1963–8[a] M	1963–8[a] F
No perception of light	10.0	5.9	4.6	3.4	4.9	5.1
Perception of light	19.8	17.1	13.4	10.4	10.9	10.4
Hand movements up to 3/60 Snellen	65.4	54.4	55.8	58.8	53.7	55.7
Better than 3/60 Snellen	4.1	22.6	26.2	27.4	30.5	28.8
Not stated	0.7					

Data from Sorsby.[11–15]

[a] Only presented disaggregated for males and females.



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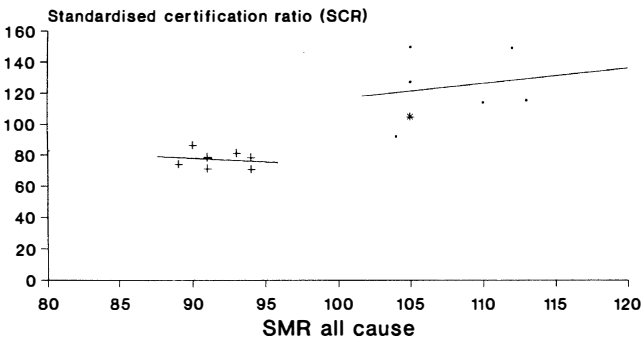

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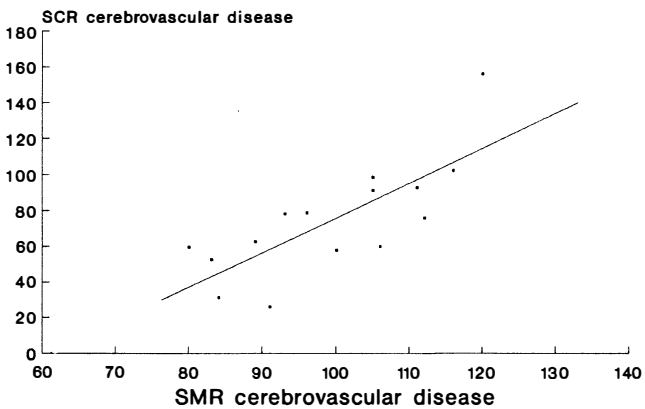

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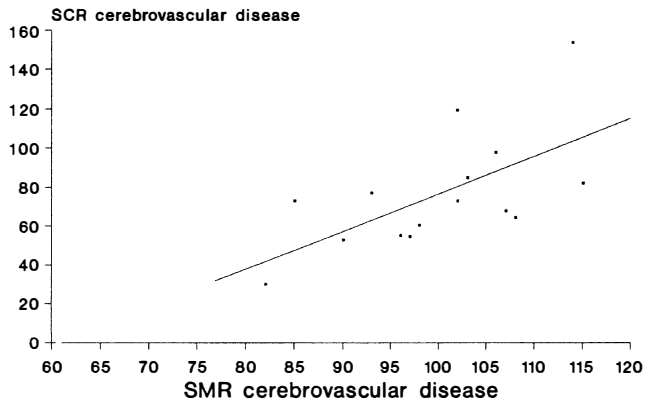

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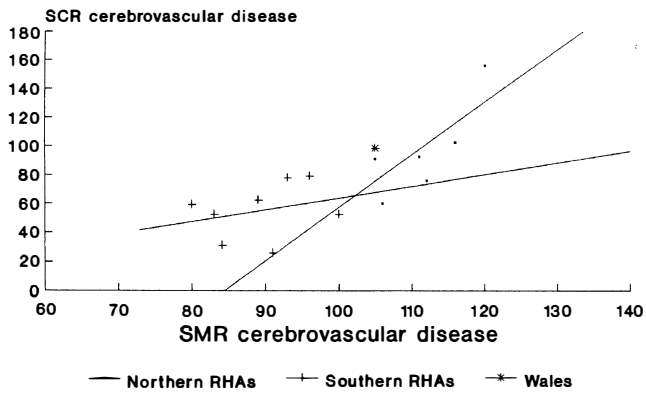

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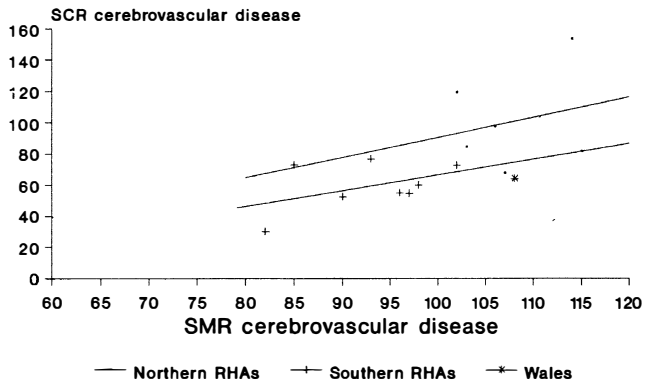

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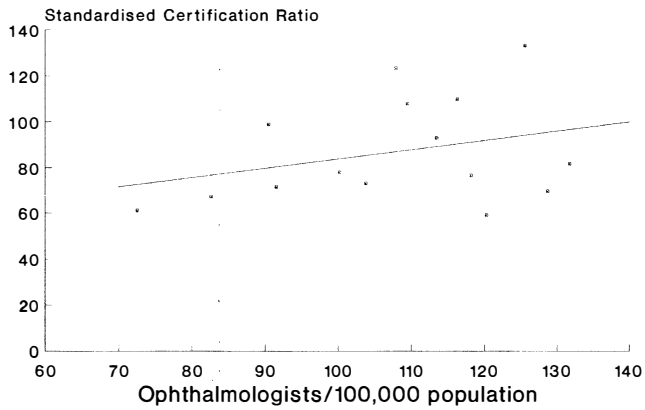

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Fig. 4. *(a) and (b) All certifications (SCR) and all-cause mortality (SMR) in males: (a) Regional Health Authorities (RHA) 1990; (b) northern/southern RHAs 1990. (c) and (d) Cerebrovascular disease certification (SCR) and mortality (SMR) by RHA 1990: (c) males; (d) females. (e) and (f) Cerebrovascular disease certification (SCR) and mortality (SMR) by northern/southern RHAs 1990: (e) males; (f) females. (g) Certifications (SCR) and ophthalmologists per 100 000 population by RHA 1990. (All certifications June–November 1990.)*

Table IV. Causes of blindness and partial sight: percentage change in main cause analysis if information on rest of form is used

Disease	Recorded as main cause		Mentioned elsewhere		% change in main cause analysis
	No. of records	Probably correct	No. of records	Probably main cause	
Degeneration of macula and posterior pole	7120	6341	9039	934	+2.2
Glaucoma	1425	1333	2406	45	−3.3
Cataract	608	558	3623	40	−1.6
Diabetic retinopathy	443	425	576	95	+17.4

of diabetic retinopathy. Of 1416 certificates where diabetes or diabetic retinopathy were mentioned, 542 were definite (i.e. diabetic retinopathy recorded and coded as the main cause), 101 probable and 563 possible diabetic retinopathy. This gives a possible range of cases of diabetic retinopathy certified as blind or partially sighted as between 542 and 1206 cases, i.e. between 3.1% and 6.8% of all certificates received in the 6-month period.

DISCUSSION

Two sources of routinely collected data are now available on the visually disabled population in England and Wales. Local authorities report the numbers of people registered each year to the DH and OPCS maintains an anonymous database of cause derived from computerisation of part 5 of the BD8 certificates – the Blind and Partially Sighted Survey (BPSS). Currently the latter constitutes a remarkable body of data: it documents the cause of visual impairment in every one of nearly 35 000 people as they are certified as eligible for registration each year.

Epidemiology is the study of the distribution and determinants of disease in populations and approaches to its control. Epidemiological analyses rest on comparisons of rates of disease in different populations and over time. The extent of any changes or differences can be used to develop or test hypotheses on aetiology, or to evaluate the effect of interventions. Therefore, a basic prerequisite for data on registration and certification to inform us as to the epidemiology of visual disability, is that every person in the population who fulfils the criteria for registration should have a BD8 form completed. In addition, the cause of blindness or partial sight should be consistently and accurately recorded. In this evaluation we have critically examined three aspects: definitions of visual disability; coverage of registration and certification; and accuracy of cause coding.

Table V. Cases of diabetic retinopathy in 1416 records on BPSS database (June–November 1990) where diabetes (ICD-9 code '250') or diabetic retinopathy (ICD-9 code '3620') mentioned

Grading	Description	Number
Definitely	Main cause = diabetic retinopathy (DRET)	542
Probably	Main cause = blank/diabetes/unspecified retinopathy	101
Possibly[a]	First ophthalmic condition right and left = DRET	563
Not	No other condition mentioned	210

[a] The following types of records were taken to be possible diabetic retinopathy: all records where diabetic retinopathy was mentioned but the main cause was either left blank or coded to diabetes, unspecified retinopathy or possible sequelae of diabetic retinopathy such as retinal detachment; all records where 'degeneration of the macula and posterior pole' was coded in the presence of diabetes as the underlying cause and there was no reason to suppose it may be another cause (e.g. 'ageing maculopathy' as indicated by 'senility' as underlying cause).

Visual function is a spectrum; depending on the criteria used, large numbers of people can be included in or excluded from the definitions of visual impairment. The broad definitions of blindness and partial sight make it difficult to assess what level of visual impairment is being measured by registration and certification, and gives rise to the question as to whether the definition is interpreted consistently by different ophthalmologists and over time. We have demonstrated that there have been trends in the interpretation of these definitions since registration began, as illustrated by the proportion of people registered with visual acuity better than 3/60. National trends of overall age-adjusted registration incidence have remained fairly constant since 1975, but registration for blindness decreased while registration for partial sight has increased, which suggests that the interpretation of the cut-off between blindness and partial sight has changed during that time period. An analysis by Shankland Cox for the Royal National Institute for the Blind (RNIB)[16] showed that while the overall rate of registration in Scotland was similar to England, age-standardised registration rates for blind and partially sighted people differed considerably. They suggested that the cut-off between blindness and partial sight was being interpreted differently in the two countries.

In the absence of clear definitions as to what constitutes visual disability, it is not surprising that different studies have produced different estimates of the degree of under-registration. The literature on evaluation of registration has focused on this aspect.[17–19] The most recent estimates have come from the RNIB survey published at the end of 1991. They estimated that blindness and partial sight are under-registered by 64% and 77% respectively.[20]

Accuracy of cause is more difficult to establish. Examination of other sources of routinely collected data on morbidity for cerebrovascular disease suggests that there is good correlation between mortality from this condition and certification for visual disability attributed to this cause. Ecological analyses always needs to be interpreted cautiously because associations at the population level are not always observed at the individual level. In this context, although average area values on mortality from cerebrovascular disease correlate strongly with average values for certification from this cause, it cannot be assumed that this

is because both sources of data reflect underlying incidence of this condition. There is still the possibility that another feature of the Regional Health Authorities, for example their geographical location, is associated with both mortality and certification. It is unlikely, however, that these correlations are caused by artefacts in the data collection systems, because the two systems are administratively completely separate. There are no data available on a national level examining the percentage of eligible patients offered BD8 certification by ophthalmologists. However, Fig. 4(g) is a plot of the SCRs against the number of consultant ophthalmologists per head of population in the Regional Health Authorities. There was some evidence of increased certification rates in areas with larger numbers of ophthalmologists; however, this trend was not significant ($p = 0.252$).

There are brief instructions for filling in the form. However, several ambiguities remain: How should main cause be recorded when there is a different cause of visual disability in either eye or when there are several ophthalmic conditions affecting vision? To what level of detail should main cause be recorded? Should all ophthalmic conditions be recorded or only those thought to be causing visual loss? What is meant by the most 'important' condition – the one which has most impact on visual function, the one most in evidence, or the most preventable cause? As regards the 'disease causing the ophthalmic condition' can ophthalmic diseases which cause other ophthalmic conditions which cause visual loss be recorded here?

The link between the people filling in the form, the coding process and analysis is crucial in presenting accurate counts by cause. Using the example of diabetic retinopathy, arguably the most important preventable cause of blindness in Britain, we have demonstrated some of the problems that may arise in analysis of computerised data of this type. These problems were revealed as a result of specific and intensive analysis, and can largely be remedied by manual reclassification. Given the scale of the data collection process (nearly 35 000 forms in the course of the first year) and level of resources currently devoted to administration and analysis, it is simply not feasible to investigate all causes of visual disability in a similar manner. In the light of the first year's experience, guidelines need to be developed by the appropriate authorities as to how to fill in part 5 of the BD8 form. Once these guidelines are implemented, there is likely to be some improvement in the quality of the data collected. However, many demands are made on consultant ophthalmologists to fill in a plethora of forms, the outcome of which they rarely see. One option to assist the accurate completion of these forms may well be to develop a system whereby the disease categories are coded at the point at which the form is completed, with or without the use of automatic disease coding software. This would effectively by-pass several stages of data completion of the form and data coding.

Incomplete coverage, inconsistent interpretation of the definitions of blindness and partial sight and possible misclassification of disease means that the interpretation of statistics collected during the registration process is not straightforward. There is no reason to suppose that BD8 certification will ever provide a useful measure of the prevalence of visual disability in the community and, indeed, there is no reason why it should. Any person attending the hospital eye service with a treatable condition will, it is hoped, be treated appropriately and discharged. Other measures will have to be developed to measure the incidence and prevalence of the major blinding eye diseases in Britain; for example, focused population-based prevalence and incidence studies. However, it is also of vital importance that the prevalence and incidence of causes of permanent visual loss are monitored, because they have implications partly for the planning of social and rehabilitation services but also in the monitoring and evaluation of preventive measures and in the exploration of the epidemiology of blinding diseases for development of hypotheses on aetiology and prevention.

By careful examination and quantification of potential sources of bias in the BPSS data, and by using judgement as to which parts of the data are useful and which misleading, this large body of information potentially provides a wealth of information for surveillance of causes of blinding eye disease, health service evaluation and research.

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Key words: BD8 certification, Registration, Visual disability.

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