

## Unrecognised and unregistered visual impairment

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### Abstract

Recent community based studies have shown that only a minority of visually impaired people who are eligible to be registered as partially sighted or blind are actually registered as such. To determine how many unregistered but eligible people are attending ophthalmic clinics a prospective study was undertaken of all patients (n=1543) attending ophthalmic outpatient departments, at a single specialty eye hospital and two district general hospitals over a 1 week period. All patients with visual acuity  $\leq 6/18$  or restricted visual field were interviewed. Registration status and factors affecting this were then determined. Although 95/174 patients interviewed were eligible for registration, 68 as partially sighted and 27 as blind, only 46 (48.4%) of these were registered. Asians and Afro-Caribbeans were under-represented in the group eligible for registration. Active treatment impeded registration. Patients having four or more hospital visits were on average 16 times more likely to be registered as those who had fewer attendances. Disabilities, in addition to visual impairment, were present in 40% (n=38). This study shows that there is unregistered visual impairment in patients attending ophthalmic departments. As registration triggers multi-disciplinary support, ophthalmologists need to be more alert to the benefits and criteria for partial sight and blind registration.

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Two recent population based surveys in Britain by the Royal National Institute for the Blind (RNIB) reported that many visually impaired people, despite being eligible, were not registered as either blind or partially sighted.<sup>1,2</sup> This was age dependent with 60% of the visually impaired under 60 years being registered, whereas by 75 years this had fallen to 13%. It is estimated that in the UK underregistration affects a staggering 200 000 blind and 400 000 partially sighted people.<sup>1</sup>

Sixty seven per cent of the visually impaired suffer additional health problems and 35% have a hearing loss (22% 16-59 years, and 37% at 75 years). They are more likely to live alone and in rented local authority accommodation. In addition, employment prospects are poor and a sighted person is four times more likely to be employed than a blind person. The surveys highlighted registration as the triggering event for multidisciplinary support by bringing the

needs of the visually impaired to the attention of agencies such as social and rehabilitation services. For instance, 56% of those registered, but only 6% of those not registered but eligible, received visits from a social worker. All these data<sup>1,2</sup> show that the visually impaired are a disadvantaged section of the population, and for those eligible but not recognised (that is, not registered), this is unnecessarily compounded.

Registration, as blind or partially sighted, is undertaken by a consultant ophthalmologist who completes form BD8. This is pertinent, as in the RNIB survey 77% of those eligible, but not registered, had seen an eye specialist at some time.<sup>1</sup> In this community based survey the 'eye specialist' was not specified, which might in some instances have been an optometrist. Therefore, some people might not have been registered as they were not seen by an ophthalmologist. Also, further visual deterioration might have occurred following discharge from ophthalmic care. Alternatively there may be underregistration of patients attending ophthalmic outpatient departments. To explore this last possibility we have conducted a hospital based study to determine how many patients who are eligible, but not registered as either partially sighted or blind, are attending hospital ophthalmic departments. The factors affecting registration are then considered.

Strictly speaking a person is *certified* as blind or partially sighted by a consultant ophthalmologist on completion of form BD8 and, on receipt of this form, this individual is subsequently *registered* by the local authority. Nevertheless, as the completion of form BD8 is generally referred to as blind or partial sight *registration*, we have continued to use this more familiar meaning of the term throughout this paper.

### Methods

Three ophthalmic units were selected: a large single specialty hospital (SSH) combining secondary and tertiary functions (Birmingham and Midland Eye Hospital) and two ophthalmic units in district general hospitals (DGHs), Shrewsbury and Telford, which share the same ophthalmic medical staff. All general and special interest ophthalmic and optometric clinics were screened. We examined prospectively the notes of all new and review patients attending these outpatient departments over a 1 week period in October 1992.

The study inclusion criteria were: best corrected Snellen visual acuity of  $\leq 6/18$ , in the

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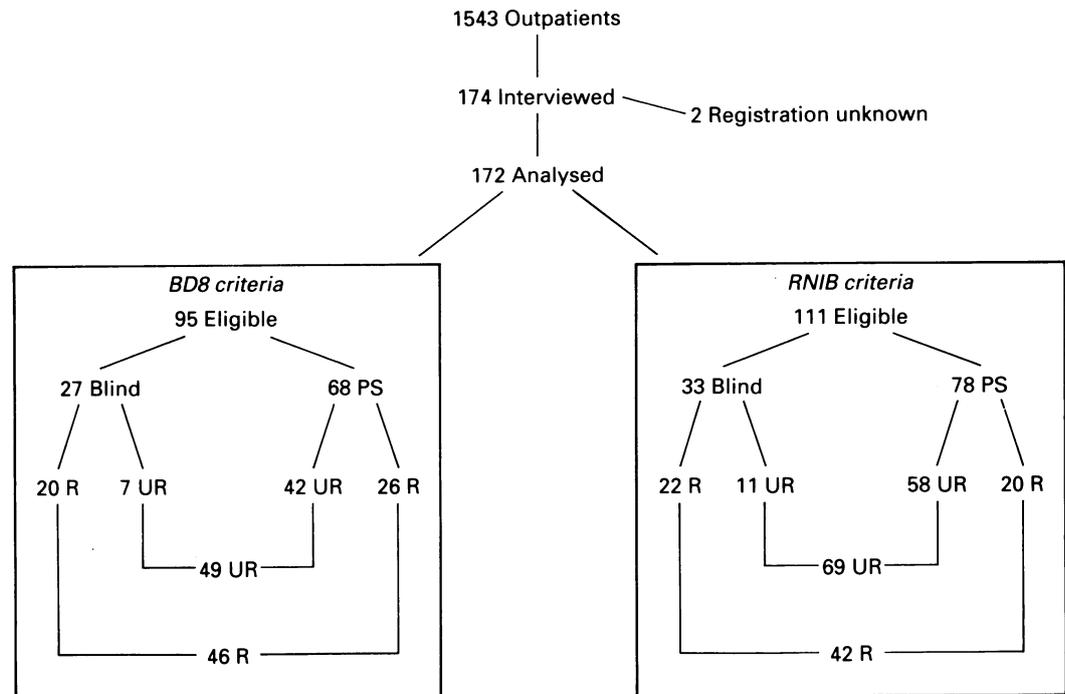


Figure 1 Registration status of the total population using the RNIB and the BD8 criteria. The left and right limbs of the diagram show the breakdown according to the BD8 and RNIB criteria respectively. (PS=partial sight, R=registered, UR=unregistered.)

better eye, on the day of visit; or a restricted visual field regardless of the visual acuity. Those meeting these criteria were interviewed. The following data were collected on each patient: demographic data, number of hospital visits for eye related problems, distance visual acuity, visual fields, ophthalmic and systemic diagnoses, any other disability, visual prognosis, and registration status. For those registered, the time and category of registration was obtained. Clinical data were obtained from the patient's notes where possible. Each patient was then interviewed by an ophthalmologist on the day of clinic attendance to obtain any missing demographic or clinical data, and to determine the reason for non-registration.

Of those interviewed, their eligibility for registration was calculated by two different means using the criteria of the RNIB survey and that of form BD8:

- (1) RNIB needs survey criteria
  - (i) Partial sight if visual acuity\* 6/24-6/60
  - (ii) Blind if visual acuity <6/60 (visual field was not taken into consideration)
- (2) BD8 criteria:

- (i) Partial sight if visual acuity
  - (a) 6/60-3/60 with a full field or
  - (b) 6/24-6/36 with a moderate contraction of the visual field, opacities in the media, or aphakia or
  - (c) 6/18 or better, if there is a gross field defect.

There is no legal definition of partial sight, however the above are the guidelines issued on the BD8 form.

- (ii) Blind if visual acuity <3/60 or ≤6/60 with severe contraction of the visual field.

In this study a third group of patients was also identified: those with visual acuity 6/24 to 6/36 who met the RNIB partial sight criteria but were not eligible for registration by the BD8 criteria – that is, the patient did not have a restricted visual field, opacity in the media, or aphakia (for example, age-related macular degeneration (ARMD) but no cataract). This third category we termed the '6/24-6/36 group'.

The patient's primary condition was classified as treatable or non-treatable. The former included some conditions with a permanent visual deficit which continue to require treatment – for example, glaucoma or diabetic retinopathy. The defect was classified as temporary when there was no co-existing pathology and there was a good treatment prognosis (for example, isolated cataract); uncertain in conditions in which the visual prognosis, even with treatment, could not be anticipated (for example, the cataract of Still's disease or diabetic maculopathy); and permanent where recovery could not occur (for example, ARMD and retinitis pigmentosa).

For the purpose of analysis the two DGHs were regarded as one. The catchment populations of the SSH and the DGH were determined from census records. The units were compared using the  $\chi^2$  test or Fisher's exact test. The  $\chi^2$  test was also used to determine individual factors affecting registration, for the group as a whole.

\*Throughout text 'visual acuity' refers to best corrected visual acuity.

Table 1 Age distribution of the total population, the SSH, and the DGH

| Age (years) | Total eligible | SSH eligible | Total pop W B'ham | DGH eligible | Total pop Shropshire |
|-------------|----------------|--------------|-------------------|--------------|----------------------|
| <16         | 8 (8.4)        | 8 (10.1)     | 51 313 (25.3)     | 0 (0.0)      | 82 627 (20.3)        |
| 16-49       | 10 (10.5)      | 10 (12.7)    | 95 138 (46.8)     | 0 (0.0)      | 195 253 (48.0)       |
| 50-65       | 11 (11.6)      | 11 (13.9)    | 28 758 (14.2)     | 0 (0.0)      | 65 464 (16.1)        |
| 66-79       | 27 (28.4)      | 21 (26.6)    | 21 561 (10.6)     | 6 (37.5)     | 48 964 (12.0)        |
| 80+         | 39 (41.1)      | 29 (36.7)    | 6 312 (3.1)       | 10 (62.5)    | 14 079 (3.5)         |
| Total       | 95 (100.0)     | 79 (100.0)   | 203 082 (100.0)   | 16 (100.0)   | 406 387 (100.0)      |

Columns 2, 3, and 5 show the age distribution of the entire cohort, SSH, and DGH respectively. Column 4 shows the population of West Birmingham which is served by the SSH and column 6 the population of Shropshire which is served by the two DGH centres. Percentages in parentheses.

Table 2 Registration status in West Birmingham by ethnic group

| Ethnic group   | Total pop W B'ham | SSH eligible | SSH registered |
|----------------|-------------------|--------------|----------------|
| White          | 121 352 (59.8)    | 71 (89.9)    | 33 (86.8)      |
| Afro-Caribbean | 27 105 (13.3)     | 3 (3.8)      | 2 (5.3)        |
| Asian          | 48 730 (24.0)     | 5 (6.3)      | 3 (7.9)        |
| Other          | 5 895 (2.9)       | 0 (0.0)      | 0 (0.0)        |
| Total          | 203 082 (100.0)   | 79 (100.0)   | 38 (100.0)     |

Column 2 shows the estimated ethnic distribution of West Birmingham. Columns 3 and 4 show, respectively, the eligible and registered patients in the SSH group. Asian and Afro-Caribbean populations constitute 37.3% of the West Birmingham community but only 10.1% of the visually impaired. Percentages in parentheses.

Logistic regression was then applied to assess independently each variable's effect on registration and odds ratios calculated to estimate the magnitude of any significant effects.

### Results

During the study period 1543 new and review patients attended ophthalmic outpatient clinics – 200 DGH and 1343 SSH; 26 DGH and 148 SSH patients met the inclusion criteria and were interviewed. Registration status could not be ascertained in two patients and the analysis was conducted on the remaining 172 cases.

Figure 1 shows the breakdown according to the RNIB survey and BD8 criteria. Using the BD8 criteria: 49/95 (51.6%) eligible for registration were unregistered, seven as blind and 42 as partially sighted. Using the RNIB criteria: 69/111 (62.2%) eligible for registration were unregistered, 11 as blind and 58 as partially sighted.

The '6/24–6/36 group' contained 27 patients of which 23 had permanent visual loss. Twenty (74%) had retinal pathology as follows: nine ARMD, five diabetic retinopathy, six other retinal pathology involving the macula.

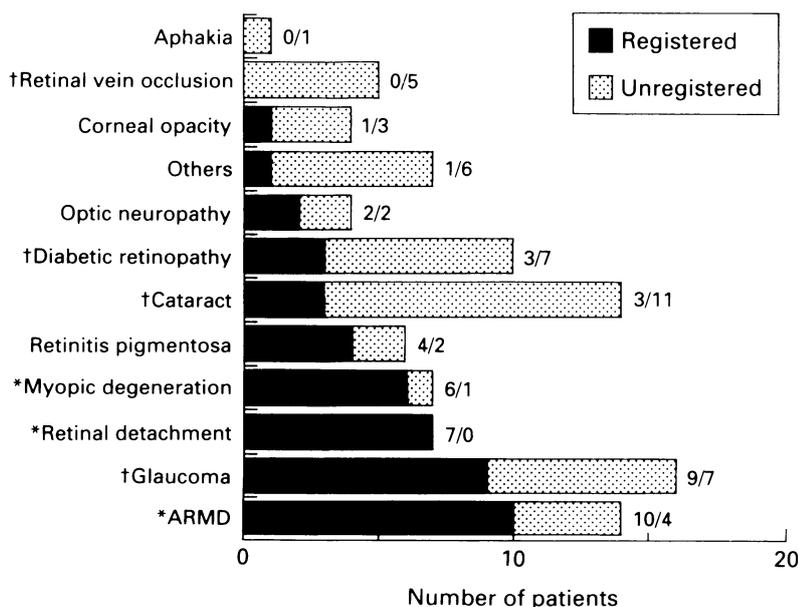


Figure 2 Ophthalmic diagnosis and registration status. The population as a whole is shown according to the diagnosis. Each horizontal line shows the number registered and unregistered for each diagnosis. Three of the major causes of registration were patients who were not receiving treatment (\*). The group who were eligible, but not registered, contained a number (†) who were receiving active ophthalmic treatment showing that ophthalmic treatment may retard the registration process.

The remaining results relate only to BD8 registration as these are the criteria used in the UK. Table 1 shows the age distribution of the eligible group as a whole, the SSH and DGH individually, the estimated age distribution for West Birmingham, which is served by the SSH, and for Shropshire which is served by both the DGHs. The table shows increasing eligibility for registration with age.

All unregistered patients at the DGHs were white. The ethnic composition of Shropshire is 98.4% white. Table 2 shows the distribution of ethnic groups eligible for registration and the population breakdown for West Birmingham. Our eligible population contains more whites and fewer Afro-Caribbean and Asians than would be expected from the ethnic distribution of West Birmingham. As the number of whites cannot be an overestimate, this indicates that certain ethnic groups of this community are not proportionately represented in this study. This suggests that significantly fewer Afro-Caribbeans and Asians attended hospital than might be expected from the population estimates ( $p < 0.001$ ).

At the SSH, 38/79 (48%) and for the DGH 11/16 (69%) of those eligible were not registered. There was no significant difference between the SSH and the DGH in the proportion eligible but unregistered ( $p = 0.13$ ). Table 3 compares the SSH and the DGH eligible populations. There was no significant difference between the SSH and the DGH with respect to sex, socioeconomic group, ethnic distribution, number of hospital visits, presence of another disability including deafness, or whether eligible for blind or partial sight registration. They differed significantly with respect to age ( $p = 0.002$ ), treatment category ( $p = 0.006$ ), and whether the visual loss was deemed permanent or temporary ( $p = 0.002$ ). All the eligible patients attending the DGH were

Table 3 Comparison of the SSH and DGH eligible populations

|                               | SSH | DGH | p Value |
|-------------------------------|-----|-----|---------|
| Age:                          |     |     |         |
| ≤65                           | 29  | 0   |         |
| >65                           | 50  | 16  | 0.002*  |
| Sex:                          |     |     |         |
| Male                          | 34  | 7   |         |
| Female                        | 45  | 9   | 0.96    |
| Race:                         |     |     |         |
| White                         | 71  | 16  |         |
| Other                         | 8   | 0   | 0.34*   |
| Socioeconomic group:          |     |     |         |
| 1                             | 6   | 3   |         |
| 2                             | 12  | 2   |         |
| 3                             | 21  | 6   |         |
| 4                             | 19  | 2   | 0.41    |
| Other disability:             |     |     |         |
| Yes                           | 30  | 8   |         |
| No                            | 44  | 8   | 0.49    |
| BD8 eligibility:              |     |     |         |
| Blind                         | 20  | 4   |         |
| PS                            | 59  | 12  | 0.97    |
| No of hospital visits:        |     |     |         |
| <4                            | 16  | 5   |         |
| ≥4                            | 61  | 11  | 0.37    |
| Treatment category:           |     |     |         |
| Treatable                     | 34  | 13  |         |
| Non-treatable                 | 44  | 3   | 0.006   |
| Permanence of visual deficit: |     |     |         |
| Permanent                     | 60  | 7   |         |
| Uncertain                     | 11  | 2   |         |
| Temporary                     | 7   | 7   | 0.002   |

The  $\chi^2$  test was used to compare the SSH and DGH for each variable. The significance is shown by the p value in column 5. \*Fisher's exact test used.

Table 4 Comparison of the registered and unregistered populations

|                               | R  | UR | p Value |
|-------------------------------|----|----|---------|
| Age:                          |    |    |         |
| ≤65                           | 16 | 13 |         |
| >65                           | 30 | 36 | 0.38    |
| Sex:                          |    |    |         |
| Male                          | 18 | 23 |         |
| Female                        | 28 | 26 | 0.44    |
| Race:                         |    |    |         |
| White                         | 43 | 44 |         |
| Other                         | 3  | 5  | 0.52    |
| Socioeconomic group:          |    |    |         |
| 1                             | 6  | 3  |         |
| 2                             | 7  | 7  |         |
| 3                             | 12 | 15 |         |
| 4                             | 8  | 13 | 0.54    |
| Other disability:             |    |    |         |
| Yes                           | 20 | 18 |         |
| No                            | 25 | 27 | 0.67    |
| BD8 eligibility:              |    |    |         |
| Blind                         | 17 | 7  |         |
| PS                            | 29 | 42 | 0.01    |
| No of hospital visits:        |    |    |         |
| <4                            | 2  | 19 |         |
| ≥4                            | 43 | 29 | <0.001  |
| Treatment category:           |    |    |         |
| Treatable                     | 15 | 32 |         |
| Non-treatable                 | 31 | 16 | <0.001  |
| Permanence of visual deficit: |    |    |         |
| Permanent                     | 44 | 23 |         |
| Uncertain                     | 1  | 12 |         |
| Temporary                     | 1  | 13 | <0.001  |

The  $\chi^2$  test was used to compare the registered and unregistered populations for each variable. The significance is shown by the p value in column 5. (R=registered, UR=unregistered.)

over 65 years whereas only 29/50 (63%) attending the SSH were under 65 years.

Table 4 compares the registered and unregistered populations, using univariate analysis. There was no significant difference for age, ethnic group, sex, socioeconomic group, and presence of another disability. Figure 2 demonstrates the primary ophthalmic diagnosis in the registered and unregistered groups. Using logistic regression non-registration was significantly higher in patients with treatable conditions ( $p=0.005$ ) even though the visual deficit may be permanent. Patients with non-treatable diseases were five times more likely to be registered as those receiving active treatment. Patients with permanent loss were more likely to be registered than either those with temporary visual loss or those where the ultimate visual outcome of treatment was uncertain ( $p<0.001$ ). Moreover, patients were 16 times more likely to be registered if they had more than four visits to the hospital ( $p<0.001$ ). Although eligibility for blind or partial sight registration was significant with univariate analysis ( $p=0.01$ ) this was not significant when the above factors were taken into consideration with logistic regression.

Figure 3 demonstrates the reasons for non-registration, 16/19 (84%) for whom the reason was not known came from the SSH. Combining SSH and DGH groups, the socioeconomic (SE) status of unregistered/registered cases was as follows: SE group 1, 3/9 (33.3%); SE group 2, 7/14 (50%); SE group 3, 15/27 (55.6%); and SE group 4, 13/21 (61.9%). This indicates a trend towards non-registration in the lower socioeconomic groups which did not reach significance.

## Discussion

There is significant underregistration of blind

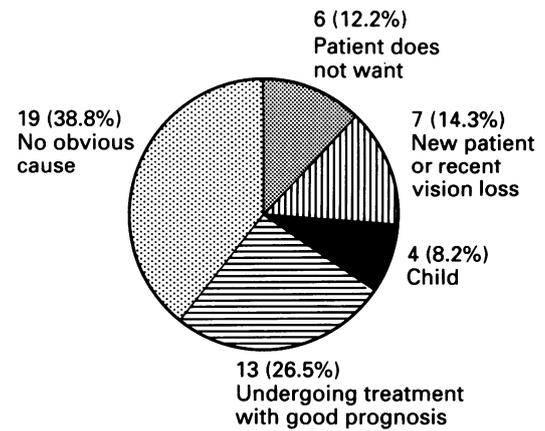


Figure 3 The reasons for non-registration as being blind or partially sighted. Percentages in parentheses.

and partially sighted patients attending ophthalmic outpatient departments. There are certain limitations of our study: the period of data collection was short and, in addition, the SSH population is biased towards special interests and does not reflect accurately the prevalence of ocular pathology in the West Midlands community. For instance, all those under 65 years eligible for registration were from the SSH rather than the DGHs.

Using the RNIB and BD8 criteria respectively (Fig 1), underregistration was 62.2% (partially sighted 74%, blind 33%) and 51.6% (partially sighted 62%, blind 26%). It is not surprising that the magnitude of underregistration in this hospital based study is lower than the population based RNIB surveys, as a number of studies have shown undetected visual impairment in the community.<sup>3-6</sup> Brennan and Knox<sup>7</sup> found substantial regional variation in the rates of registration that could not be explained by demographic differences alone and concluded that this must be due to variations in behaviour by patients, doctors, and social workers. As with the RNIB surveys<sup>1,2</sup> a high proportion of those eligible for registration in our study (38/95 – that is, 40%) also had an additional disability of mobility, deafness, or learning difficulty.

Although, in our study, age did not significantly affect registration, most of the unregistered patients were elderly with 36/49 (73.5%) over 65 years (Table 1). This highlights the fact that many unregistered patients are pensioners, already on a low income and often with other disabilities.

Certain ethnic sections of the Birmingham population appear to be underrepresented (Table 2). These figures must be interpreted with caution as the SSH receives referrals from areas other than West Birmingham. Nevertheless the Afro-Caribbean and Asian population of West Birmingham, estimated at 13.3% and 24% respectively, are significantly underrepresented ( $p<0.001$ ). These data suggest that either certain ethnic groups do not gain access to ophthalmic services or, most unlikely, have a lower prevalence of visual loss from ophthalmic disease than whites. The Baltimore Eye Study<sup>6</sup> showed significantly higher rates of blindness in blacks compared with whites in almost all age groups. There is no comparable information on Asians in

the UK. Once reaching hospital there is no difference in the registration rate between ethnic groups. We do not know whether low access affects certain ethnic groups nationwide as we only studied two areas, one of which (Shropshire) is 98.4% white.

The causes of blindness and partial sight are broadly similar to other studies.<sup>8-11</sup> In the non-registered group the major causes of visual impairment encountered were cataract, glaucoma, diabetic retinopathy, retinal vein occlusion, and ARMD in descending order of frequency, which together accounted for 69.3% (34/49) of this category (Fig 2).

Ophthalmic diagnosis and treatment may influence registration, and those patients due for discharge are five times more likely to be registered than a chronic attender. ARMD, myopic degeneration, and retinal detachment are examples of the former and were among the most frequent diagnoses (23/46, 50%) in the registered group, whereas glaucoma, diabetic retinopathy, and retinal vein occlusion still requiring review accounted for 19 (39%) of the non-registered patients. Thus active treatment of a chronic ophthalmic disorder can inhibit registration. Perhaps in this situation professional preoccupation lies with treatment rather than daily living support. Many untreatable cases are discharged at a time when they are not eligible for registration – for example, only one eye affected by ARMD. Deterioration may subsequently occur in the community (for example, in the other eye) and the patient may not gain access back to the hospital service, because of long waiting lists, or alternatively access is not sought because either the patient or the general practitioner does not consider it worthwhile, as ‘nothing can be done’.

Six (12.2%) patients in our study declined the offer of registration, perhaps because it is frequently seen by patients and professionals alike as a negative act rather than as a trigger initiating support. In a postal survey of the blind register by Graham *et al*<sup>12</sup> many who were eligible but not registered were opposed to registration, considering it a form of charity. Ophthalmologists need to emphasise the positive aspects of registration although it may not be appropriate on the first examination and in children and young adults. Registration is also inappropriate where the visual loss is temporary with good prognosis – for example, cataract. In our opinion these patients should not be registered but should be given a high priority to have their vision restored.

USA and WHO registration criteria are based on acuity alone (USA criteria 6/12 and  $\leq 6/60$ , and WHO criteria 6/18 and  $< 3/60$ , for partial sight and blind registration respectively). The criteria for partial sight registration in the UK are unhelpfully vague and do not adequately account for the functional consequences of the visual deficit. This problem is highlighted by the ‘6/24–6/36 group’ who are not eligible for BD8 registration despite reduced acuity, as they do not have the additional criteria of a reduced field,

opacity in the media, or aphakia. Yet, as many (20/27) have distorted vision due to central retinal disturbance, they are in fact functionally more disabled than many of those who are eligible. By making BD8 criteria fall in line with the WHO criteria, all the patients in this group would be eligible for registration.

#### CONCLUSIONS

Registration may be perceived by professionals and patients as a negative act of doubtful benefit. This is far from true and ophthalmologists and primary care workers need to be more alert to the benefits and criteria for blind and partial sight registration. Without delineating individual benefits of partial sight and blind registration, generally those not registered do not receive support.<sup>1</sup> We have found that those least likely to be registered are the elderly, probably ethnic minorities, and patients undergoing treatment for chronic ophthalmic problems. As registration triggers support the registration process needs to be facilitated, and perhaps ophthalmologists other than consultants should be able to complete form BD8. There are certain anachronisms, so that some visually disabled patients are not eligible for registration (‘6/24–6/36 group’). These should be overcome, and the process of partial sight registration should be modified to take into account the functional consequences of the ophthalmic disorder. New strategies are required to ensure that the visually impaired within and without the hospital service get the support they need but currently lack.

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