# **BMJ Open** Certification for vision impairment: researching perceptions, processes and practicalities in health and social care professionals and patients

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#### ABSTRACT

**Objectives:** To explore the patient experience, and the role of ophthalmologists and other health and social care professionals in the certification and registration processes and examine the main barriers to the timely certification of patients.

Design: Qualitative study.

**Setting:** Telephone interviews with health and social care professionals and patients in three areas in England.

**Participants:** 43 health and social care professionals who are part of the certification or registration process. 46 patients certified as severely sight impaired (blind) or sight impaired (partially sighted) within the previous 12 months.

**Results:** Certification and registration are life changing for patients and the help they receive can substantially improve their lives. Despite this, ophthalmologists often found it difficult to ascertain when it is appropriate to certify patients, particularly for people with long-term conditions. Ophthalmologists varied in their comprehension of the certification process and many regarded certification as the 'final stage' in treatment. Administrative procedures meant the process of certification and registration could vary from a few weeks to many months. The avoidable delays in completing certification can be helped by Eye Clinic Liaison Officers (ECLO).

**Conclusions:** A better understanding of the certification and registration processes can help improve standards of support and service provision for people who are severely sighted impaired or sight impaired. Better education and support are required for ophthalmologists in recognising the importance of timely referral for rehabilitative support through certification and registration. ECLOs can improve the process of certification and registration. Finally, better education is needed for patients on the benefits of certification and registration.

#### INTRODUCTION

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose

#### Strengths and limitations of this study

- This is the first study to focus on all those involved in the certification and registration processes—various health and social care professionals as well as patients.
- The research design includes areas with differing rates of certification demonstrating and showing the opportunities to improve practice to ensure the certification process is more consistent.
- The number of participants was small, so findings should be considered indicative, however, saturation/repetition levels were reached in all three interview groups, suggesting confidence in the findings.
- All patients were certified, further research is needed to explore why patients decline certification.

is to provide a reliable route for someone with sight loss to be brought to the attention of social care.

Certification and registration are two separate processes: an ophthalmologist completes the CVI based on existing visual function criteria and support needs and the hospital sends the CVI to the patient's social services. Patients can be certified as sight impaired (SI-formerly 'partial sighted') or severe sight impairment (SSI-formerly 'blind') (see box 1 for an overview of criteria). Local Social Service Departments (SSDs) then initiate the registration process on receipt of the completed CVI. Registration is voluntary; as such, SSDs ask patients if they would like to be registered. When patients are certified as either SSI or SI they are eligible for a range of support including: financial concessions (eg, tax breaks, free NHS sight tests), welfare benefits and the loan of aids and equipment. Data collected by CVI also provides valuable epidemiological information on the prevalence of sight loss.

## **Box 1** Definitions of sight impaired (SI) and severe sight impairment (SSI)

To be registered as severely SI (blind), sight has to fall into one of the following categories, while wearing any glasses or contact lenses that one may need:

- Visual acuity of less than 3/60 with a full visual field;
- Visual acuity between 3/60 and 6/60 with a severe reduction of field of vision, such as tunnel vision;
- Visual acuity of 6/60 or above but with a very reduced field of vision, especially if a lot of sight is missing in the lower part of the field.

To be registered as SI (partially sighted) sight has to fall into one of the following categories, while wearing any glasses or contact lenses that one may need:

- Visual acuity of 3/60 to 6/60 with a full field of vision;
- Visual acuity of up to 6/24 with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry;
- Visual acuity of up to 6/18 if a large part of your field of vision, for example a whole half of your vision, is missing or a lot of your peripheral vision is missing.<sup>1</sup>

Further information on Certificate of Vision Impairment can be found on the Royal College of Ophthalmology webpage: http://www.rcophth.ac.uk/page.asp?section=851&search.

There is concern that the number of CVIs should be as accurate as possible as the Public Health Outcomes Framework in England, introduced in 2013, includes an indicator for preventable sight loss for the first time. The indicator aims to better target financial resources to improve early detection of the three major causes of sight loss (glaucoma, age-related macular degeneration (AMD) and diabetic retinopathy).<sup>2</sup> As the CVI includes causes of vision impairment, it will provide a metric for levels of avoidable sight loss for the indicator. It is therefore important that the number and information in CVIs and subsequent registrations reflect accurate levels of need.

However, evidence shows the numbers of certifications and registrations have varied considerably over time and in many cases numbers have declined. This is in addition to the increasing prevalence of sight loss accompanied by the ageing population in the UK.<sup>3</sup> In the 12 months from April 2008 to March 2009, the number of certifications was 23 773, a marked increase on the previous 12 months.<sup>4</sup> Certifications then decreased in 2009/2010 and 2010/2011, before rising to 23 616 in 2011/2012.<sup>5</sup> Similarly, the triennial survey of people registered with Councils with Adult Social Services Responsibilities in England as being SSI or SI showed an overall decrease in new registrations in 2010/2011 compared with 2008/2009.<sup>6</sup>

Perhaps even more noteworthy is the large geographical variation found to exist in rates of severe sight impairment and sight impairment, with an 11-fold difference found to exist between the highest and lowest rate, according to 2008/2009 data.<sup>7</sup> This paper examines the certification and registration processes in hospitals and social services departments and identifies the main barriers, delays and enablers. It also explores the significance of certification and registration for patients.

#### MATERIALS AND METHODS Sample

A qualitative study was designed based on semistructured telephone interviews of clinical and social care providers and service users.<sup>8</sup> The study was undertaken in three separate areas of England identified as having fluctuating rates of sight loss certification between 2006 and 2011.<sup>9</sup> NHS research ethics approval was secured for each hospital site. Forty-three health and social care professionals and 46 patients were interviewed by an experienced interviewer (see table 1). The term 'patient' is used throughout this article instead of 'client' or 'service user'. This is for continuity and clarity.

Hospital and social services staff interviews were with: ophthalmologists, optometrists and nurses working in ophthalmology departments, social services rehabilitation officers, social services administrators, Eye Clinic Liaison Officers (ECLOs) and hospital administration staff (see table 1). All ophthalmologists interviewed were consultants except one trainee registrar. Of the 11 consultants interviewed, 2 were qualified for less than 2 years; the remaining 9 consultants were qualified for over 10 years. Hospital interviewees were identified by their head of department. Social care interviewees were identified by ECLOs and a representative from local visual impairment forums.

Patients with vision impairment (and two primary carers) were interviewed. Patients were identified by ECLOs or social services. As patients' recollections of medical consultations can be poor within relatively short periods after a consultation,<sup>10</sup> only patients certified within the last year were interviewed. Interviewees included patients certified and registered (n=32), those certified only (n=5) and those certified but unsure if they were registered (n=9). A sampling frame was created to direct patient recruitment. The sample frame aimed to ensure a diversity of patients in terms of age, ethnicity, gender and income.<sup>11</sup>

Fifteen per cent (n=7) of patients classified themselves as Asian, 7% (n=3) African-American and the remainder Caucasian (n=36). Forty-one per cent (n=19) stated they had an income below £15 000/annum. Sixty-three per cent (n=29) of patients were over 60 years of age and 57% (n=26) were women. Compared with national CVI figures,

Table 1 Number of interviews by type and area		
Area A	Area B	Area C
10 Hospital staff	13 Hospital staff	8 Hospital staff
1 Social services	9 Social services	2 Social services
15 Patients	15 Patients	16 Patients
Total: 26	Total: 37	Total: 26

African-American and Minority Ethnic patients were over represented and the gender characteristics of the sample were comparable with national demographics.<sup>12</sup>

#### Interviews and data analysis

Semistructured telephone interviews were conducted with individual participants at a time that suited the interviewees. Interviews lasted on average for 15 min; although some were substantially longer (patient interviews ranged from 8 to 40 min, interviews with health/ social care professionals ranged from 6 to 50 min). Topics for discussion were predefined by the consensus of the research steering group. Interviews with professionals sought to explore: (1) knowledge and understanding of certification and registration; (2) local pathways and the factors affecting certification and registration; (3) the role of different health and social care professionals and (4) the future of certification and registration and suggestions for improvement. Interviews with patients explored: (1) experiences of being certified and registered; (2) the impact of certification and registration on the lives of patients and their families and (3) suggestions for improvement (see boxes 2-4).

Interview questions acted as a guide and additional information was also gleaned.

All interviews were recorded, transcribed and analysed using thematic analysis. A list of deductive codes was initially created; inductive codes emerged during the second level of the thematic analysis.<sup>14–16</sup>

The findings are illustrated with extracts from the interviews. Extracts are referenced with the type of interviewee and interview number—patient (Pat); ophthalmologist (Ophth); secretary/administrator (Adm); nurse (Nur); optometrist (Optom); eye clinic liaison officer (ECLO); social services staff including managers, rehabilitation officers, administrators (SS).

It was observed that the terms 'certification' and 'registration' were used incorrectly and inconsistently by most interviewees; hence these terms were amended in the text to provide clarity.

#### RESULTS

The research findings are grouped into overarching themes. Despite the differences in size, location and

<b>Box 2</b> Themes in ophthalmology/optometrist/nurs	se
Certificate of Vision Impairment (CVI) process/when you recommend certification Purpose of CVI What you tell patients about CVI Barriers to approaching patients Length to complete CVI Knowledge of benefits of being certified Reasons for decline Improvements	n-

**Box 3** Themes in administrators/Eye Clinic Liaison Officers questions

Certificate of Vision Impairment (CVI) process Length from receiving CVI to sending to social services Purpose of CVI Improvements

demography of the three areas, there was considerable consistency in the findings. There were, however, local variations in the certification and registration processes.

#### Knowledge and awareness of the purpose and benefits of certification and registration

Many health professionals were poorly informed about the purpose and benefits of certification and registration. Almost every health professional was unaware that there was a difference between certification and registration. The terms 'certified' and 'registered' were interchanged throughout all interviews. Most health professionals assumed registration happened automatically once a patient was certified at the hospital.

That's really weird. I thought if we certified the patients we automatically registered them with social services. I'm really surprised to hear that. (Nur2)

Consequently, only a small number of health professionals were aware of what SSDs offered to certified and registered patients.

(SS provide) enormous echelons of help, home visits, advice about lighting, advice about managing in home when you've got visual impairment, enormous levels of support that you don't need to be registered to get that support. Great to have ECLO to access this cause that's their expertise. (Ophth6)

#### Uncertainty when to certify the patient

The point at which certification was offered to patients varied between clinicians. The difference was less a geographic trend and more related to the individual clinician's approach.

Ophthalmologists identified difficulties in subjective interpretation of visual field defect and fluctuating visual function as potential reasons why the offer of certification may be inconsistent or delayed. Ophthalmologists also highlighted the impact of recent advancements in treatment on the decision of when to certify a patient.

The whole issue itself is subjective... It depends on the clinician, assessing the visual field and interpreting that. (Ophth10)

#### **Box 4** Themes in patient questions

Experiences of being certified and registered, length to complete Access to support before certification

People with AMD with injections go up and down... Once they have reached certifiable level, a lot of time we couldn't do anything and historically we would have offered certification. Now they will have a few more injections, they get a little better. (Ophth11)

Most ophthalmologists stated that they based their decisions on *when* to offer certification primarily on visual acuity; they did not consider the patient's functionality or the level of support they might need. Half of the ophthalmologists (n=6) reported relying solely on quantitative visual function (ie, acuity or visual field).

In contrast, almost all optometrists and nurses interviewed considered a patient's functionality when deciding whether or not to recommend certification.

I don't look at it from the medical point of view rather from the social point of view. I do try to ask everybody who would fit the criteria and I probably try to engage more the people maybe I think would benefit from being registered, someone by themselves, could do with help from social services. (Nur2)

## Certification as the end of the process, not a route to services

Approximately half of the ophthalmologists (n=5) regarded certification as the 'final stage' in the management of a patient's condition, only offered to the patient at the *end* of their treatment.

I think in practice (certification) does tend to coincide with an acknowledgement that there's little more that we can offer them medically...Certification can often form part of a process towards the end of a period of medical care and so it often coincides with their discharge from hospital or their discharge from a period of follow-up. (Ophth5)

In contrast, patients very much regarded certification as a significant point in their treatment, stating it was the beginning of a stage of acceptance of their sight loss. The offer of certification was emotionally overwhelming for almost every patient interviewed (n=41); the help they received at this time vastly improved the quality of their lives.

Interviewer: Has registration helped you?

Absolutely, 100%. (Pat26)

#### Administrative barriers to certification and registration

The length of time to complete the certification and registration process varied within each area and across the three sites. Patients reported the length of time for them to go through certification and registration ranged from a few weeks to close to 1 year.

It took quite a while, and for (hospital) to send out information like CVI and all that. (Pat25) SS was a long time getting the information from the hospital...My son and daughter-in-law called them because no one contacted us. (Pat26)

Social services staff also reported variability in the length of time it took for CVIs to be sent to them, a finding confirmed by hospital administrative staff. Hospital workload and delays in obtaining authorisation for the CVI were cited as key barriers.

Sometimes (CVIs) are there for a while, sometimes varies. Another consultant who gets a lot, he has a quick turnaround, he fills out the bulk of them, get one day and then a day or two after that...Can sit on desks longer if they are away, week or a bit longer. (Adm4)

Delays also occurred as a result of incomplete CVIs being sent to SSDs. One SS interviewee estimated half of the CVIs they receive have an incorrect or missing telephone number and this delayed the registration process.

The ophthalmologist hasn't indicated whether the patient is considered SI or SSI or has omitted to sign it or a page could be missing altogether. When this happens we have to send the CVI back with a covering letter which delays disability registration and can delay services for the patient. (SS5)

An additional practice that unnecessarily delays sending certifications to SS is waiting to send CVIs in batches. All SS staff (n=12) stated they received CVIs in batches. Patients also reported variations in the length of time it took social services to contact and/or visit them. This was confirmed by interviews with social services staff.

Apparently they were meant to put me in touch. I've been on a waiting list for nearly 4 months and nobody's got in touch with me...I'm still waiting; I'm still on a list. (Pat42)

Sensory team used to be part of bigger team that had two admin workers, did have bigger team, now have parttime rehab, no admin, manager not in the building, massive change. (SS6)

There were repercussions of these delays, close to half (20/46 patients, 43%) stated they would have liked to have been offered certification earlier, to access support. The purpose of the CVI, to prompt access to holistic low vision and sensory support, is much valued by patients and many would benefit from being offered or receiving this support as early as possible.

#### The role of clinic support staff and the ECLO

Each hospital eye clinic had an ECLO in post but the role of the ECLO in the certification and registration process differed in each hospital. The function of the ECLO was dictated largely by ophthalmologists' perception of the ECLO's role. <u>6</u>

The presence of an ECLO was viewed as beneficial by all patients and the majority of staff. Most ophthalmologists (N=9) agreed it was more cost-effective and a better use of their time if ECLOs helped to complete the CVI and participate in the certification process. Although the ECLOs said they were often used inconsistently by ophthalmologists.

I must say that ECLO was brilliant. She talked us through what was going to happen, what we had to do, literally I didn't do much after that... I literally came out of the door and met ECLO...That made a huge difference to me. (Pat23)

ECLO offered help...gave me time to think about it... and I needed time...she was very sympathetic and did her job beautifully. (Pat2)

I much prefer (sending patients to ECLO) because when you're in a situation where you're seeing patients in clinical setting you're under a lot of pressure because you've got a certain number of patients to see and the time is ticking. (Opt3)

Biggest positive for us has been the ECLO—irons out difficulties in liaising with different agencies and informing the patients about the benefits and the sources of help they can get. Made a big difference in my practice. (Ophth10)

#### The patient benefit of certification and registration

The certification and registration processes were an emotionally overwhelming time for almost all patients and they described the help they receive at this time as substantially improving their lives. The support offered as a result of being certified and registered changed lives and made patients more confident.

I used to sit crying a great deal before these things started feeding through to me, from social services. I have a certain amount of confidence back...I lost all of that at one time. (Pat37)

It's all about confidence, my confidence went to zero. The more things you can do for yourself, more confident with, makes your life better. (Pat23)

The practical assistance that resulted from certified and registered was also valued by patients.

I faced my fear thinking I'd never walk in the dark anymore and thanks to social services, they've trained me to walk in the dark. (Pat14)

[social services] issued me with bus pass, made me more mobile, fold up white stick, recognition stick, helps an immense amount. (Pat31)

#### Improving the certification and registration process

Suggestions to improve certification and registration included initiatives to improve health professionals' level

of awareness about the benefits of being certified and registered. In one area studied, the SSD worked collaboratively with consultants to improve patients' experiences of certification and registration.

Greater use of the ECLO was also a common theme suggested to improve the service. In one area social services said the number of incomplete forms decreased since an ECLO was employed, stating that previously 10–15% CVIs received would be sent back as they were incomplete. Ophthalmologists also commented on the difference ECLOs make to provide accurate and detailed information to patients.

I'm happy to provide what support I can but I'd readily agree that I don't have the time and I don't think I'm as good as the ECLO because I think most of us assume what patients want and need. We spend our lives making decisions for them with our expertise and experience...I don't have the time on the day...and the ECLO does and so wonderfully. (Ophth1)

In many areas the third sector played a key role in providing support to patients who were extremely grateful for this assistance. Where support from SSDs took longer to arrive, the role of the voluntary sector was invaluable.

We contacted Action for Blind and they helped filled out forms with... I've learned more from RNIB/Action than anyone else. (Pat39)

Age Concern was brilliant...people would be in a complete panic quite honestly if you were on your own and you had to come home on your own and then you suddenly got to cope with all this stuff. (Pat5)

#### DISCUSSION

The current study examined the process of sight loss certification and registration in three areas in England in order to identify potential barriers and delays in timely certification and registration and possible options for improving the service.

Despite the ageing population and predicted increases in those with sight loss,<sup>17</sup> the numbers of people certified each year with sight loss have declined in recent years, with the exception of the 12 months from April 2011 to March 2012, which showed a marked increase on previous years. A significant geographical variation also exists across England in certification rates of severe sight impairment and sight impairment.<sup>7</sup> These variations in rates of certification and registration have been attributed to differences in the level at which certification is being offered, care pathways, perceived value of certification and registration and payment for CVI forms. However, this information is largely anecdotal and this is the only study to directly explore the sight loss certification and registration pathways.

In our study, ophthalmologists revealed they are often uncertain as to when to offer certification. For some patients it is clearly evident when their eye sight has reached the point to be certified but for others deciding when to certify is more ambiguous. Research finds higher under-registration in patients with treatable disease compared with those with untreatable disease.<sup>18</sup> The uncertainty of when to certify was also an issue for other eye conditions.<sup>19</sup> For example, certifying patients with atrophic AMD also presents significant timing difficulties.<sup>20</sup> These patients often experience severe sight loss after discharge but need to be referred back into the hospital eye service for certification when their vision declines. Introducing these patients to the ECLO/ social services team before they are discharged will improve their access to relevant support services.

Some ophthalmologists are unclear of the purpose of certification which may affect when they offer it to patients. Consultants may delay certifying patients as they regard certification as the end of a clinical process and wait to certify patients until they think they cannot offer any further medical treatments. Related to the issue of when to offer certification is the reason for offering it: the purpose of certification is to provide access to support for patients. Certification and registration are not simply medical processes but a significant step in patients' adjusting and accepting of their sight-loss. Interviews with patients revealed the issuing of certification is often viewed as the beginning of a new phase and a gateway to much needed support. In contrast, many ophthalmologists regard certification as the end of the process but this attitude can lead to patients needing support left without it.

There was variation in the certification process in each of the three areas and the process used by each consultant differed within hospitals. The department of health recommends the CVI be sent to the local social services department 'within five working days'.<sup>21</sup> Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within 5 days. It was much more common for CVIs to take weeks or months to be sent to SSDs. Previous research also found that delays often occur when CVIs are sent to SSDs.<sup>22</sup> Each administrator (n=8) confirmed consultants can 'take a while' to return the CVI to their office. Another significant delay is sending incomplete CVIs to SSDs; an unnecessary delay for patients waiting for support.

These practices lengthen the certification and registration processes, making it more complicated and unnecessarily fraught for patients. In each of the three areas studied, there were examples of good and bad practices and stories of both grateful and frustrated patients, thus a good certification process is achievable in every department.

A more holistic approach to eye health is needed; health professionals, including registrars, ophthalmologists, optometrists and medical secretaries should improve their awareness of when certification should be offered and how certification benefits patients. Any additional time needed for CVI discussion in clinic may not be readily available due to pressures on quantity (eg, meeting Referral to Treatment guidance and other performance targets), therefore departments should explore if others, such as optometrists or ECLOs, are better placed to complete parts of the CVI. It should also be considered who is best placed to send completed CVIs quickly—ECLOs or secretaries or a designated administrator/team.

Understanding how certification and registration operates at a local level will help commissioners and clinicians better understand the reasons for the variations in certification and registration rates and take steps to address the inconsistencies. Quantifying the barriers to timely certification and registration, and benchmarking against best practice will also help ensure the correct level of service provision, enabling health and social care commissioners to deliver consistent, high quality services based on an accurate assessment of need.

#### Limitations of research

The interviews include only those who were certified, further research could examine patients who are eligible for certification but who either decline to be certified or are not offered it by clinicians. In addition, as the research used qualitative methods, we were able to interview a limited number of health and social care professionals. Further research is needed to examine a wider range of departments over a longer period of time. Research is also needed to understand the impact of the Disability Living Allowance assessment policies and whether there is any pressure on ophthalmologists not to certify patients.

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#### REFERENCES

 RNIB. Vision criteria for registration. RNIB, 2014. http://www.rnib.org. uk/livingwithsightloss/registeringsightloss/Pages/vision\_criteria.aspx (accessed 18 Jan 2014).

### 6

- Department of Health. Public health outcomes framework 2013 to 2016 and technical updates. DH, 2013. https://www.gov.uk/ government/publications/healthy-lives-healthy-people-improvingoutcomes-and-supporting-transparency (accessed 18 Jan 2014).
- RNIB. Sight loss UK 2012—the latest evidence. RNIB, 2012. http:// www.rnib.org.uk/aboutus/Research/reports/otherresearch/Pages/ sight\_loss\_uk.aspx (accessed 17 Jan 2014).
- Leamon S. Number of adults and children certified with sight impairment and severe sight impairment in England and Wales: April 2008—March 2009. RNIB, 2012. http://www.rnib.org.uk/aboutus/ Research/reports/otherresearch/Pages/sight\_loss\_statistics\_report. aspx (accessed 17 Jan 2014).
- Leamon S. Number of adults and children certified with sight impairment and severe sight impairment in England and Wales: April 2011-March 2012. RNIB, 2013. http://www.rnib.org.uk/aboutus/ Research/reports/otherresearch/Pages/sight\_loss\_statistics\_report. aspx (accessed 17 Jan 2014).
- The NHS Information Centre, Adult Social Care Team. Registered blind and partially sighted people Year ending 31 March 2011, England. NHS Information Centre, 2011. http://www.hscic.gov.uk/ pubs/blindpartiallysighted11 (accessed 17 Jan 2014).
- Malik ANJ, Bunce C, Wormald R, et al. Geographical variation in certification rates of blindness and sight impairment in England, 2008–2009. BMJOpen 2012;2:e001496.
- 8. Britten N. Qualitative interviews in medical research. *BMJ* 1995;311:251–3.
- Boyce T. The certification and registration processes: stages, barriers and delays. RNIB, 2012. http://www.rnib.org.uk/aboutus/ Research/reports/earlyreach/Pages/certification\_registration\_ processes.aspx (accessed 17 Jan 2014).
- McGuire LC. Remembering what the doctor said: Organization and adults—memory for medical information. *Exp Aging Res* 1996;22: 403–28.
- 11. McLean RJ, Windridge KC, Gottlob I. Living with nystagmus: a qualitative study. *Br J Ophthalmol* 2012;96:981–6.

- Office for National Statistics. Annual mid-year population estimates, 2011 and 2012. ONS, 2013. http://www.ons.gov.uk/ons/rel/popestimate/population-estimates-for-uk-england-and-wales-scotlandand-northern-ireland/mid-2011-and-mid-2012/stb—mid-2011—mid-2012-uk-population-estimates.html#tab-Mid-2011-and-mid-2012-UKpopulation-estimates- (accessed 17 Jan 2014).
- Office for National Statistics. *Population estimates by ethnic group:* methodology paper. ONS, 2011. http://www.ons.gov.uk/ons/ taxonomy/index.html?nscl=Population+Estimates+by+Ethnic+Group (accessed 17 Jan 2014).
- 14. Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. 2nd edn. London: Sage Publications, 1994.
- Morse JM, Field PA. Qualitative research methods for health professionals. 2nd edn. London: Sage Publications, 1995.
- 16. Maxwell JA. *Qualitative research design. An interactive approach.* 2nd edn. London: Sage Publications, 2005.
- Leamon S. Number of adults and children certified with sight impairment in England and Wales: April 2011-March 2012. RNIB, 2013. http://www.mib.org.uk/aboutus/Research/reports/otherresearch/ Pages/sight\_loss\_statistics\_report.aspx (accessed 17 Jan 2014).
- Kotecha A, Fernandes S, Bunce C, et al. Avoidable sight loss from glaucoma: is it unavoidable? Br J Ophthalmol 2012;96:816e820.
- 19. Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8.
- Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? *Eye* 2012;26:933–6.
- Department of Health. Certificate of vision impairment explanatory notes for consultant ophthalmologists and hospital eye clinic staff. https://www.gov.uk/government/uploads/system/uploads/attachment\_ data/file/127399/CVI-Explanatory-notes-in-DH-template.pdf.pdf (accessed 17 Jan 2014).
- Bunce C, Smyth L, Xing W, et al. (ND) Research into drop in registrations of blind and partially sighted people. (Supplied by first author, available from TB).