Certification for vision impairment – perceptions, process and practicalities

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004319
Article Type:	Research
Date Submitted by the Author:	23-Oct-2013
Complete List of Authors:	Boyce, Tammy; Imperial College, Medicine Slade, John; RNIB, Simkiss, Phillippa; RNIB, Judd Street rughani, sonal; RNIB, Judd Street Ghanchi, Faruque; Bradford Royal Infirmary, Ophthalmology
Primary Subject Heading:	Ophthalmology
Secondary Subject Heading:	Qualitative research, Evidence based practice, Health policy, Medical education and training, Public health
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, OPHTHALMOLOGY, PREVENTIVE MEDICINE, QUALITATIVE RESEARCH

Title:

Certification for vision impairment – perceptions, process and practicalities

Keywords:

Blindness; Visually Impaired Persons; Certification of Vision Impairment;

Professional-Patient Relations

Authors:

Dr T Boyce (Corresponding)
Department of Medicine
Imperial College
London

30 Victoria Park Rd East
Cardiff
CF5 1EH
<tboyce@imperial.ac.uk>

Mr J Slade
Royal National Institute of Blind People (RNIB)
105 Judd Street
London
WC1H 9NE
020 7388 1266

Dr P Simkiss
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Ms S Rughani
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr Faruque Ghanchi
Bradford Teaching Hospitals NHS Foundation Trust
Duckworth Lane
Bradford
BD9 6RJ
01274 382386

Abstract

Objectives

To evaluate the processes for Certification of Vision Impairment, examine the role of ophthalmologists and health and social care professionals in the

Design

Qualitative.

Setting

Telephone interviews with health and social care professionals and patients from three sites in England examining experiences of the certification and registration processes.

Participants

43 health and social care professionals involved in the certification or registration process and 46 patients certified as blind or partially sighted within previous 12 months.

Results

The process of being certified is separate from being registered for vision impairment. Deciding at what point a patient should be certified can be uncertain and ophthalmologists varied in their comprehension of the certification process. The length of time to complete the certification and registration process varies from a few weeks to many months. The avoidable delays in completion and forwarding of the CVIs to social services can be helped by Eye Clinic Liaison Officers (ECLO).

Conclusion

Visual function is the key aspect to consider when offering a patient CVI. Being certified with vision impairment is a significant process for patients that can

substantially change their lives. Eye Clinic Liaison Officers can improve the process of being certified and registered.

Article summary

Strengths and limitations of this study

- This is the first study to study those involved in the certification and registration processes, including health and social care professionals and patients.
- The number of participants was small, so findings should be considered indicative, however repetition levels were reached in all three interview groups suggesting confidence in the findings.
- Further research is needed to understand the impact of new Disability Living Allowance assessment policies and whether there is any pressure on ophthalmologists not to certify patients and explore patients who are eligible but not certified.

Introduction

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose 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. Patients can be certified as sight impaired (SI – formerly 'partial sighted') or severe sight impairment (SSI- formerly 'blind'). Local Social Service Department (SSDs) then initiate the registration process upon receipt of the completed CVI. Registration is a voluntary choice, as such, SSDs ask patients if they would like to be registered.

There has been an inconsistent decline in both the number of certifications and number of registrations in many areas of England, though the ageing population would suggest an increase in certifications.[1] There is also concern that the number of CVIs is 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).[2] 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.

This paper examines the certification processes in hospitals and identifies the main barriers, delays and enablers with particular emphasis on the role of ophthalmologists. It also explores the significance of certification for patients.

Materials and Methods

Sample

A qualitative study was designed based on semi-structured telephone interviews of clinical and social care providers and service users.[3][4] The study was undertaken at three separate areas of England identified as having inconsistent CVI registration rates between 2006 and 2011. NHS research ethics approval was secured for each hospital site. 43 health and social care professionals and 46 patients were interviewed by an experienced interviewer (See Table 1). These interviewed included; ophthalmologists (12), ECLOs (4), Nurses (3), Optometrists (4) and Administrators (8). All ophthalmologists interviewed were consultants except one trainee registrar. Of the eleven consultants interviewed, two were qualified for less than two years; the remaining nine consultants were qualified for over ten years. Hospital interviewees were identified by their head of department. Social care interviewees were identified by ECLOs and a representative from the London Visual Impairment Forum.

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,[5] only patients certified within the last year were interviewed. Interviewees included patients certified and registered and those only certified.

A sampling frame was created to direct patient recruitment. The sample frame aimed to ensure age, ethnicity, gender and income variation.

One fifth (n=11) of patients identified as Asian/Black and 41% stated they had an income below £15,000/annum. 63% were over 60 years of age and 26 out of 46 interviews were with women.

Interviews and Data Analysis

Telephone interviews were arranged with individual participant's agreement at a time that suited the interviewees. Interviews lasted on average for 15 minutes, although some were substantially longer (Patients range 8-40 minutes, health/social care professionals range 6-50 minutes). The interviews were based on semi-structured questions that were predefined by the consensus of the research team. Interview questions included descriptions of their role in the certification process (See Box 1-3).

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

Box 1: Themes in ophthalmology/optometrist/nurse questions

CVI process Length from receiving CVI to sending to social services Purpose of CVI Improvements

Box 2: Themes in administrators/ ECLO questions

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

Box 3: Themes in patient questions

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.[6,7,8]

The interviewees are described using a number and labels – patient (Pat), ophthalmologist (Oph), secretaries and administrators (Adm) and social services staff- 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. In addition, the term 'patient' is used throughout the report instead of 'client' or 'service user'. This is for continuity and clarity.

Results

There were subtle differences in process for certification in the three areas and the clinicians differed in the timing of offer of certification to the patients. The difference was not so much a geographic trend but related to individual clinician's approach. It was not possible to conclude in this research if differences in certification processes are due to systematic issues or individual practices.

A significant difference between hospitals was the length of time for CVIs to be sent to SSDs. Within each of the three geographic areas studied social services responded that it took from one week to many months for CVIs to be sent to them:

> 'Between 10 days and three or four months.' (SS2)
>
> 'Some received few days later, others take 3 months.' (SS4)

Delays also occur as incomplete CVIs are sent to SSDs. One SS interviewee estimated half of the CVIs they receive have the wrong or no telephone number and this delayed the C&R process;

> 'The standard of completion of CVIs is extraordinarily poor…You have to tick whether SSI or SI, quite regularly they'll have ticked the wrong box.' (SS11)

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.

In each of the three areas, patients confirmed the length of time for them to go through both C&R varied from a few weeks to close to one year. There was also variation within each department, with some patients stating C&R took a few weeks whilst others stated it took many months.

The eye clinics differed in their approach to use of the ECLO service for certification and registration process. ECLOs helped complete the CVI in two areas, however one factor that contributed to the inconsistent certification

process in hospitals was ophthalmologists' attitudes towards ECLOs. All four ECLOs said ophthalmologists used them inconsistently. One consultant agreed;

> 'At the moment I keep forgetting (laughs). I'm meant to send to ECLO…He's not here for all of my clinics.' (Oph1)

Three quarters of the ophthalmologists (N=9) agreed it would be cost-effective and would be better use of their time if ECLOs helped to complete the CVI (Part 3) and participate in the certification process;

> 'I'm fairly senseless when it comes to a list of benefits they are entitled to, I think the ECLO is brilliant at explaining the other benefits like tax, entitled to this and that, parking.' (Oph9)
>
> '(Completing CVI) does eat into clinic time, someone else can do it.' (Oph2)

The interviewed ophthalmologists identified difficulties in subjective interpretation of visual field defect and fluctuating visual function as potential reasons why the offer of certification may be delayed.

> 'The whole issue itself is subjective… It depends on the clinician, assessing the visual field and interpreting that.' (Oph10)

One ophthalmologist described the difficulty of certifying people with AMD, as with recent antiVEGF treatments visual improvement may be possible, and fluctuating visual acuity levels can influence certification process.

> 'People with AMD with injections go up and down like a yo-yo. 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.' (Oph11)

Similarly, some of the Consultants responded highlighting that similar issues in certifying patients with other eye conditions for example for patients with diabetic retinopathy[9].

> 'We know with diabetics when you've got some degree of visual impairment you've also got peripheral field changes because of the diabetic retinopathy and the lasering - there's a whole mass of grey area in there.' (Oph6)

Most ophthalmologists stated they based their decisions on when to offer certification on visual acuity: many did not consider a patient's functionality or the level of support a patient might need. Half of the ophthalmologists (n=6) admitted they relied only on quantitative visual function (acuity or field) when deciding whether or not to offer certification, they did not consider a patients' support needs.

> 'making the decision, use visual acuity, based on visual fields, and then work out if eligible (Interviewer: Do you think about support at home?) You decide whether or not they are eligible and whether or not it will be of benefit for them is a separate issue.' (Oph8)

Some of the ophthalmologists (n=4) took account of a patient's practical visual needs when considering to offer certification.

> '(If patients) highlight particular problems they are having…problems with seeing dials for thermostats, looking for instructions for things, could do with help regarding lighting even, if they ever talk about safety issues like gas fires or cookers or have burnt themselves I tend to worry more about safety…I think of offering low vision support as a package.' (Oph1)

Similar to the majority of the ophthalmologists, all three nurses interviewed stated that visual function was a primary factor in their decision whether to recommend certification.

Consultants appeared more likely to offer certification at the end of their treatment, they (n=5) often described how they regard certification as the 'final stage' in the management of the eye condition;

> '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.' (Oph5)

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?'

Pat26: 'Absolutely, 100%.'

The practical assistance that resulted from certified and registered was valued most by patients;

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

'(SS) issued me with bus pass, made me more mobile, fold up white stick, recognition stick, helps an immense amount.' (Pat31)

Discussion

The aim of this research was to examine the inconsistent decline in the number of certifications issued since the CVI was introduced in England in September 2005. Despite the ageing population and predicted increases in those with sight loss[10], there has been an inconsistent decline in both the number of certifications and number of registrations. Between 2010/11 and 2011/12 there

was a 4% *increase* in the number of certifications in England[10] In contrast, between 2008/09 and 2009/10 there was a 5% *decrease* in the number of certifications.[11]

In addition the decline in new blind registrations at regional level reveals wide variations in the numbers registered.[12] The largest decline in new registrations was observed in the East Midlands, where new blind registrations decreased by 52%, while the smallest decline was in the North East - only 10% (See Figure 1).[12] Even in small geographical areas the number of CVIs and associated registrations varied widely, e.g. in inner London new registrations fell by 41% whereas in outer London the decrease was 24%.[12] Reasons for the inconsistent declines in certifications and registrations are poorly understood.[13]

Interviews with 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 to those with untreatable disease.[14] The uncertainty of when to certify was also an issue for other eye conditions.[9] For example, certifying patients with atrophic AMD also presents significant timing difficulties.[15] 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.

In addition, some ophthalmologists are unclear of the purpose of certification which may affect when they offer it. 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.[16] 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. Of the 46 patients interviewed, 20 stated they would have liked to have been offered certification earlier, to access support.

There was variation in the certification process in each of the three areas and the process used by each consultant differed within hospitals. The DH recommends the CVI be sent to the local social services department "within five working days".[17] Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within five days. It was much more common for CVIs to take weeks or months to be sent. Previous research also found that delays often occur when CVIs are sent to SSDs.[18] 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 C&R process, making it more complicated and fraught for patients. In each of the three areas studied, there were examples of good and bad practice and stories of both grateful and frustrated patients, thus a good certification process is achievable in each 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.[9] Any additional time needed for CVI discussion in clinic may not be readily available due to pressures on quantity (meeting Referral to Treatment 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.

Discussion

The certification of vision impairment is inconsistently offered by ophthalmologists. The uncertainty of when to certify may be contributing to the decline in certifications. Many ophthalmologists regard certification as the end of a process instead of regarding it as a formal route to support.

Patients have both positive and negative experiences of certification. When the C&R processes 'work', patients access support within weeks, however often

patients with vision impairment need and wish to access support before they are offered certification.

ECLOs play an important role in improving the C&R process, by making it more efficient and improving the process for consultants. Ophthalmologists may wish to consider their role beyond clinical care and utilise their skills better to offer the appropriate support to their patients. Certification changes patients' lives; ophthalmologists should acknowledge the significant role they play in helping patients access support and improve their quality of life.

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Contributorship Statement

B wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Acknowledgements:

Many thanks to the health professionals, representatives from social services and patients who participated in the interviews and took great courage in providing honest feedback on their experiences of the C&R process. Many thanks to the advisory group who provided guidance and advice.

Competing interests:

None.

Funding statement

The Royal National Institute of Blind People funded this research. The funders contributed to the design of the research.

References

1 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 7 July 2013)

2 Department of Health. *Public Health Outcomes Framework 2013 to 2016 and technical updates.* DH, 2013. https://www.gov.uk/government/news/public-health-outcomes-framework-sets-out-desired-outcomes-and-supporting-transparency (accessed 7 July 2013).

3 Boyce T. *The Certification and Registration Processes: Stages, barriers and delays.* RNIB, 2012. http://www.rnib.org.uk/aboutus/Research/reports/otherresearch/Pages/certification_registration_processes.aspx (accessed 7 July 2013).

4 Britten N. Qualitative interviews in medical research. *BMJ* 1995; **311**:251-3.

5 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.

6 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.

7 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.

8 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.

9 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8

10 Leamon S. *Number of adults and children certified with 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 7 July 2013).

11 Leamon S. *Number of adults and children certified with sight impairment in England and Wales: April 2010-March 2011*. RNIB, 2012. http://www.rnib.org.uk/aboutus/Research/reports/otherresearch/Pages/sight_loss_statistics_report.aspx (accessed 7 July 2013)

12 Malik ANJ, Bunce C, Wormald R, Suleman M, Stratton I, Muir Gray JA. Geographical variation in certification rates of blindness and sight impairment in England, 2008–2009. *BMJOpen.* 2012; 2:e001496. doi:10.1136/bmjopen-2012-001496.

13 Lake R. *A review of information needs and practice relating to people with sensory impairments*. NHS Information Centre, 2010.

14 Kotecha A, Fernandes S, Bunce C, Franks WA. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499

15 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? Eye 2012;26:933-936.

16 Department of Health. *Guidance published on registering a vision impairment as a disability*. http://www.dh.gov.uk/health/2013/01/cvi/ (accessed 7 July 2013).

17 Health and Social Care Information Centre. *People Registered as Blind and Partially Sighted - England, 2006, Triennial.* http://www.ic.nhs.uk/article/2021/Website-Search?productid=1885&q=blind+partially+sighted+2006&sort=Relevance&size=10&page=1&area=both#top (accessed 7 July 2013).

18 Bunce C, Smyth L, Xing W, Zekite A (ND) Research into drop in registrations of blind and partially sighted people. (Available from TB).

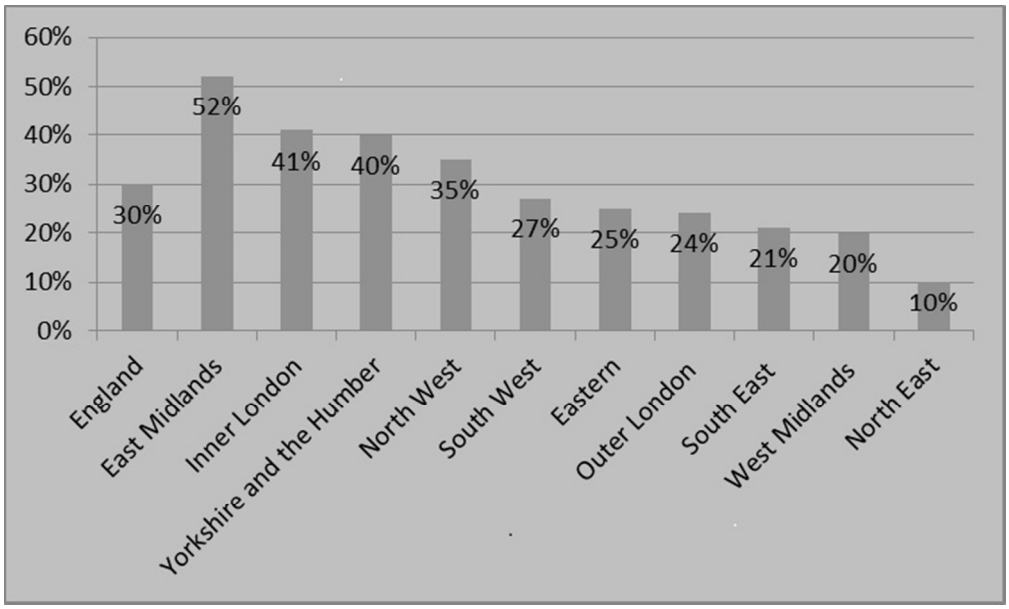

Figure 1: Decrease in new registrations by region 2003-2011(13)
197x118mm (96 x 96 DPI)

BMJ open

Certification for vision impairment – perceptions, process and practicalities

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004319.R1
Article Type:	Research
Date Submitted by the Author:	04-Feb-2014
Complete List of Authors:	Boyce, Tammy; Imperial College, Medicine Leamon, Shaun; Royal National Institute of Blind People, Slade, John; RNIB, Simkiss, Phillippa; RNIB, Judd Street rughani, sonal; RNIB, Judd Street Ghanchi, Faruque; Bradford Royal Infirmary, Ophthalmology
Primary Subject Heading:	Ophthalmology
Secondary Subject Heading:	Qualitative research, Evidence based practice, Health policy, Medical education and training, Public health
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, OPHTHALMOLOGY, PREVENTIVE MEDICINE, QUALITATIVE RESEARCH

Title:

Certification for vision impairment – perceptions, process and practicalities

Keywords:

Blindness; Visually Impaired Persons; Certification of Vision Impairment;

Professional-Patient Relations

Authors:

Dr T Boyce (Corresponding)
Department of Medicine
Imperial College
London

30 Victoria Park Rd East
Cardiff
CF5 1EH
<tboyce@imperial.ac.uk>

Mr Shaun Leamon
Royal National Institute of Blind People (RNIB)
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr J Slade
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Dr P Simkiss
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Ms S Rughani
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr Faruque Ghanchi

Bradford Teaching Hospitals NHS Foundation Trust
Duckworth Lane
Bradford
BD9 6RJ
01274 382386

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 blind or partially sighted within the previous 12 months.

Results

Certification and registration is 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).

Conclusion

A better understanding of the certification and registration processes can help drive up standards of support and service provision for blind and partially sighted people. Better education and support is 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.

Article summary

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 show 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 including this group is needed to explore why these patients are declining certification.

Introduction (count 3863)

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose 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. Patients can be certified as sight impaired (SI – formerly 'partial sighted') or severe sight impairment (SSI – formerly 'blind') (see Table 1 for an overview of criteria). Local Social Service Department (SSDs) then initiate the registration process upon 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 blind/ SSI or partially sighted/ SI the are eligible for a range of support including: financial concessions (e.g. 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.

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).[(2)] 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.[3] 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.[4] Certifications then decreased in 2009/2010 and 2010/2011, before rising to 23,616 in 2011/2012.[5] Similarly, the triennial survey of people registered with Councils with Adult Social Services Responsibilities in England as being blind or partially sighted showed an overall decreased in new registrations in 2010/2011 compared with 2008/2009.[6]

Perhaps even more noteworthy is the large geographical variation found to exist in rates of blindness and sight impairment, with an 11-fold difference found to exist between the highest and lowest rate, according to 2008/2009 data. [7]

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 semi-structured telephone interviews of clinical and social care providers and service users.[8] The study was undertaken in three separate areas of England identified as having fluctuating

rates of sight loss certification between 2006 and 2011[9]. NHS research ethics approval was secured for each hospital site. 43 health and social care professionals and 46 patients were interviewed by an experienced interviewer (See Table 2). The term 'patient' is used throughout the report 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 2). All ophthalmologists interviewed were consultants except one trainee registrar. Of the eleven consultants interviewed, two were qualified for less than two years; the remaining nine consultants were qualified for over ten 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,[10] 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.[11]

Fifteen per cent (n = 7) of patients classified themselves as Asian, seven per cent (n = 3) Black and the remainder White (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 fifty-seven per cent (n = 26) were women. Compared to national CVI figures, Black and Minority Ethnic patients were over represented and tthe gender characteristics of the sample were comparable with national demographics.[12, 13]

Interviews and Data Analysis

Semi-structured telephone interviews were conducted with individual participants at a time that suited the interviewees. Interviews lasted on average for 15 minutes; although some were substantially longer (patient interviews ranged from 8-40 minutes, interviews with health/social care professionals ranged from 6-50 minutes). 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; 3) and suggestions for improvement (See Box 1-3).

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

Box 1: Themes in ophthalmology/optometrist/nurse questions

CVI process Length from receiving CVI to sending to social services Purpose of CVI Improvements

Box 2: Themes in administrators/ ECLO questions

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

Box 3: Themes in patient questions

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.[14,15,16]

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 (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 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 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.' (Oph10)

> '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.' (Oph11)

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 (i.e. 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.' (Oph5).

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 one 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 part-time 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.

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, I'm glad she was there because you come out and you think right? What now? What does it mean? What do I do? How do I cope? And she was there. That made a huge difference to me….
> ECLO is the most wonderful person.' (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)

> ‘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.’ (Oph10)

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 providing 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.' (Oph1)

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, [17] 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

blindness and sight impairment. [7] 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 to those with untreatable disease.[18] The uncertainty of when to certify was also an issue for other eye conditions.[19] For example, certifying patients with atrophic AMD also presents significant timing difficulties.[20] 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".[21] Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within five 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.[22] 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 practice 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 (e.g. 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.

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Acknowledgements:

Many thanks to the health professionals, representatives from social services and patients who participated in the interviews and took great courage in providing honest feedback on their experiences of the C&R process. Many thanks to the advisory group who provided guidance and advice.

Funding statement

The Royal National Institute of Blind People funded this research. The funders contributed to the design of the research.

Contributorship Statement: TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Competing interests:

None.

Data Sharing Statement: We will not make any additional unpublished data available.

References

1 RNIB. *Vision criteria for registration*. RNIB, 2014. http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/vision_criteria.aspx (Accessed 18 January 2014).

2 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-improving-outcomes-and-supporting-transparency (Accessed 18 January 2014).

3 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 January 2014)

4 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 January 2014)

5 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/sigh t_loss_statistics_report.aspx (Accessed 17 January 2014)

6. 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 January 2014)

7. Malik ANJ, Bunce C, Wormald R, Suleman M, Stratton I, Muir Gray JA. Geographical variation in certification rates of blindness and sight impairment in England, 2008–2009. *BMJOpen.* 2012; 2:e001496. doi:10.1136/bmjopen-2012-001496.

8 Britten N. Qualitative interviews in medical research. *BMJ* 1995; 311:251-3.

9 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 January 2014).

10 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.

11 McLean RJ, Windridge KC, Gottlob. Living with nystagmus: A qualitative study. *Br J Ophthalmol* 2012;96:981-986 doi:10.1136/bjophthalmol-2011-301183

12 Office for National Statistics. *Annual Mid-year Population Estimates, 2011 and 2012.* ONS, 2013. http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/stb---mid-2011---mid-2012-uk-population-estimates.html#tab-Mid-2011-and-mid-2012-UK-population-estimates- (Accessed 17 January 2014).

13 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 January 2014)
14 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.
15 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.
16 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.
17 Leamon S. *Number of adults and children certified with 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 January 2014).
18 Kotecha A, Fernandes S, Bunce C, et al. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499
19 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8
20 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? *Eye* 2012;26:933-936.
21 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 January 2014).
22 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).

Table 1 Definitions of SI and SSI

To be registered as severely sight impaired (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 sight impaired (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.[(1)]

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

Table 2. 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

Title:

Certification for vision impairment – perceptions, process and practicalities

Keywords:

Blindness; Visually Impaired Persons; Certification of Vision Impairment;

Professional-Patient Relations

Authors:

Dr T Boyce (Corresponding)
Department of Medicine
Imperial College
London

30 Victoria Park Rd East
Cardiff
CF5 1EH
<tboyce@imperial.ac.uk>

Mr Shaun Leamon
Royal National Institute of Blind People (RNIB)
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr J Slade
~~Royal National Institute of Blind People (~~RNIB~~)~~
105 Judd Street
London
WC1H 9NE
020 7388 1266

Dr P Simkiss
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Ms S Rughani
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr Faruque Ghanchi

Bradford Teaching Hospitals NHS Foundation Trust
Duckworth Lane
Bradford
BD9 6RJ
01274 382386

Abstract ~~(255)~~

Objectives

To explore the patient experience ~~of sight loss evaluate the processes for certificertification and registration, cation of vision impairment (CVI) in clinical practice, examine~~ and the role of ophthalmologists and other health and social care professionals in the ~~the~~ certification and registration processes and ~~processe and~~ examine ~~s and~~ the main barriers ~~and causes for delays and~~to the timely certification ~~enablers.~~of patients.

Design

Qualitative study.

Setting

Telephone interviews ~~were held~~ with health and social care professionals and patients in three areas ~~from three sites~~ in England ~~examining their experiences of the certification and registration processes~~.

Participants

43 health and social care professionals who are part of the certification or registration process. ~~and~~ 46 patients certified as blind or partially sighted within the previous 12 months.

Results

~~The number of certificates of vision impairment (CVI) is falling inconsistently across England.~~ Certification and registration is 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. ~~The process of being certified is separate from being registered for vision impairment. Deciding at what point a patient should be certified can be uncertain and~~ ~~o~~Ophthalmologists varied in their comprehension of the certification process and ~~.~~ many regarded certification as the 'final stage' in treatment. Administrative procedures meant ~~T~~the process of ~~length of time to complete the~~ certification and registration ~~process~~ could var~~yied~~ from a few weeks to many months. The avoidable delays in completin~~gon and forwarding of the CVIs to social services~~certification can be helped by Eye Clinic Liaison Officers (ECLO).

Conclusion

A better understanding of the certification and registration processes can help drive up standards of support and service provision for blind and partially sighted people. Better education and support is 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.

~~*Visual function is the key aspect to consider when offering a patient CVI. Being certified with vision impairment is a significant process for patients that can substantially change their lives. Eye Clinic Liaison Officers can improve the process of being certified and registered.*~~

Article summary

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 show 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 including this group is needed to explore why these patients are declining certification.

Funding statement

The Royal National Institute of Blind People funded this research. The funders contributed to the design of the research.

Introduction (count 3863)

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose 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. Patients can be certified as sight impaired (SI – formerly 'partial sighted') or severe sight impairment (SSI – formerly 'blind') (see Table 1 for an overview of criteria). Local Social Service Department (SSDs) then initiate the registration process upon receipt of the completed CVI. Registration is a voluntary choice; as such, SSDs ask patients if they would like to be registered.

When patients are certified as either blind/ SSI or partially sighted/ SI the are eligible for a range of support including: financial concessions (e.g. 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.

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).[2] 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.

~~The prevalence of sight loss increases with age. The ageing population in the UK would therefore be expected to result in an increase in sight loss.[1]~~

However, evidence shows t~~T~~he numbers of certifications and registrations have varied~~show, however,~~ considerable~~ variation~~ 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.[3] 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.[4] Certifications then decreased in 2009/2010 and 2010/2011, before rising to 23,616 in 2011/2012.[5] Similarly, the triennial survey of people registered with Councils with Adult Social Services Responsibilities in England as being blind or partially sighted showed an overall decreased in new registrations in 2010/2011 compared with 2008/2009.[6] Perhaps even more noteworthy is the large geographical variation found to exist in rates of blindness and sight impairment, with an 11-fold difference found to exist between the highest and lowest rate, according to 2008/2009 data. [7]

~~There has been an inconsistent decline in both the number of certifications and number of registrations in many areas of England, though the ageing population would suggest an increase in certifications.[1] There~~ There is also concern that ~~the number of CVIs should be~~ is 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).[2] 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.~~

This paper examines the certification and registration processes in hospitals and social services departments and identifies the main barriers, delays and enablers ~~with particular emphasis on the role of ophthalmologists~~. It also explores the significance of certification and registration for patients.

Materials and Methods

Sample

A qualitative study was designed based on semi-structured telephone interviews of clinical and social care providers and service users.[8]~~4~~ The study was undertaken ~~at~~ in three separate areas of England identified as having fluctuating rates of sight loss ~~inconsistent CVI~~certification ~~registration rates~~ between 2006 and 2011[9]~~3~~. NHS research ethics approval was secured for each hospital site. 43 health and social care professionals and 46 patients were interviewed by an experienced interviewer (See Table 2~~1~~). The term 'patient' is used throughout the report instead of 'client' or 'service user'. This is for continuity and clarity.

~~The interviews with h~~Hospital and social services staff interviews were ~~included interviews~~ 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 2). ~~These interviewed included; ophthalmologists (12), ECLOs (4), Nurses (3), Optometrists (4) and Administrators (8).~~ All ophthalmologists interviewed were consultants except one trainee registrar. Of the eleven consultants interviewed, two were qualified for less than two years; the remaining nine consultants were qualified for over ten years. Hospital interviewees were identified by their head of department. Social care interviewees were identified by ECLOs and a representative from local ~~the London V~~visual ~~I~~impairment ~~F~~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,[104] only patients certified within the last year were interviewed. Interviewees included patients certified and registered (n = 32), ~~and~~ those certified only ~~certified~~(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 ~~variation~~.[115]

Fifteen per cent ~~One fifth~~ (n = 7~~11~~) of patients ~~identified~~ classified themselves as Asian, seven per cent (n = 3) ~~/~~Black and the remainder White (n = 36). Forty-one per cent (n = 19)~~41%~~ stated they had an income below £15,000/annum. Sixty-three per cent (n = 29) of patients ~~63%~~ were over 60 years of age and fifty-seven per cent (n = 26) ~~out of 46 interviews~~ were ~~with~~ women. Compared to national CVI figures, Black and Minority Ethnic patients were over represented

and t. Tthe gender characteristics of the sample were comparable with national demographics.[12, 13]

Interviews and Data Analysis

Semi-structured Ttelephone interviews were arranged conducted with individual participant's agreement at a time that suited the interviewees. Interviews lasted on average for 15 minutes,minutes; although some were substantially longer (pPatients interviews ranged from 8-40 minutes, interviews with health/social care professionals ranged from 6-50 minutes). The interviews were based on Topics for discussion were semi-structured questions that were predefined predefined by the consensus of the research steering groupteam. Interviews questions with professionals sought to explore: 1) knowledge and understanding of certification and registration; 2) local pathways and the factors affecting certification and registrationincluded descriptions of their role in the certification process; 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; 3) and suggestions for improvement (See Box 1-3).

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

Box 1: Themes in ophthalmology/optometrist/nurse questions

CVI process Length from receiving CVI to sending to social services Purpose of CVI

Improvements

Box 2: Themes in administrators/ ECLO questions

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

Box 3: Themes in patient questions

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.[14,15,16~~6,7,8~~]

The findings are illustrated with extracts from the interviews. Extracts are referenced with the type of interviewee and interview number~~The interviewees are described using a number and labels~~ – patient (Pat)~~,~~; ophthalmologist (Oph~~th~~)~~,~~; secretary~~ies and~~ /administrator~~s~~ (Adm); nurse (Nur); optometrist (Optom); Eye Clinic Liaison Officer (ECLO) ~~and~~ social services staff ~~-~~ (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. ~~In addition, the term 'patient' is used throughout the report instead of 'client' or 'service user'. This is for continuity and clarity.~~

Results

The research findings are grouped into overarching themes. Despite the differences in size, location and demography of the three areas, there was considerable consistency in the findings. There were, however, local variations in ~~subtle differences~~the certification and registration processes. ~~in process for certification in the three areas~~

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 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 ~~and the~~ clinicians~~s differed in the timing of offer of certification to the patients~~. The difference was ~~not so much~~less a geographic trend and more ~~but~~ related to the individual clinician's approach. ~~It was not possible to conclude in this research if differences in certification processes are due to systematic issues or individual practices.~~

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.' (Oph10)

'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.' (Oph11)

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 (i.e. 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.' (Oph5).

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 one 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)

~~A significant difference between hospitals was the length of time for CVIs to be sent to SSDs. Within each of the three geographic areas studied s~~Social services staff also ~~responde~~reported~~d~~ variability in the length of time it took ~~that it took from one week to many months~~ 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)
>
> ~~'Between 10 days and three or four months.' (SS2)~~
>
> ~~'Some received few days later, others take 3 months.' (SS4)~~

Delays also ~~occur~~occurred as a result of incomplete CVIs being~~are~~ sent to SSDs. One SS interviewee estimated half of the CVIs they receive have an incorrect or missing ~~the wrong or no~~ telephone number and this delayed the registration~~C&R~~ 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)
>
> ~~'The standard of completion of CVIs is extraordinarily poor…You have to tick whether SSI or SI, quite regularly they'll have ticked the wrong box.' (SS11)~~

~~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.~~

~~In each of the three areas, patients confirmed the length of time for them to go through both C&R varied from a few weeks to close to one year. There was also variation within each department, with some patients stating C&R took a few weeks whilst others stated it took many months.~~ 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 part-time 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 ~~The eye clinics differed in their approach to use of the ECLO service for certification and registration process. ECLOs helped complete the CVI in two areas, however one factor that contributed to the inconsistent certification process in hospitals was~~ ophthalmologists' perception of the ~~attitudes towards~~ECLO's role ~~ECLOs. . All four ECLOs said ophthalmologists used them inconsistently. One consultant agreed;~~

~~'At the moment I keep forgetting (laughs). I'm meant to send to ECLO…He's not here for all of my clinics.' (Oph1)~~

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, I'm glad she was there because you come out and you think right? What now? What does it mean? What do I do? How do I cope?

And she was there. That made a huge difference to me….

ECLO is the most wonderful person.' (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)

~~Three quarters of the ophthalmologists (N=9) agreed it would be cost-effective and would be better use of their time if ECLOs helped to complete the CVI (Part 3) and participate in the certification process;~~

'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.' (Oph10)

~~'I'm fairly senseless when it comes to a list of benefits they are entitled to, I think the ECLO is brilliant at explaining the other benefits like tax, entitled to this and that, parking.' (Oph9)~~

~~'(Completing CVI) does eat into clinic time, someone else can do it.' (Oph2)~~

~~The interviewed ophthalmologists identified difficulties in subjective interpretation of visual field defect and fluctuating visual function as potential reasons why the offer of certification may be delayed.~~

'The whole issue itself is subjective… It depends on the clinician, assessing the visual field and interpreting that.' (Oph10)

One ophthalmologist described the difficulty of certifying people with AMD, as with recent antiVEGF treatments visual improvement may be possible, and fluctuating visual acuity levels can influence certification process.

'People with AMD with injections go up and down like a yo-yo. 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.' (Oph11)

Similarly, some of the Consultants responded highlighting that similar issues in certifying patients with other eye conditions for example for patients with diabetic retinopathy[9].

'We know with diabetics when you've got some degree of visual impairment you've also got peripheral field changes because of the diabetic retinopathy and the lasering - there's a whole mass of grey area in there.' (Oph6)

Most ophthalmologists stated they based their decisions on when to offer certification on visual acuity: many did not consider a patient's functionality or the level of support a patient might need. Half of the ophthalmologists (n=6) admitted they relied only on quantitative visual function (acuity or field) when

deciding whether or not to offer certification, they did not consider a patients' support needs.

'making the decision, use visual acuity, based on visual fields, and then work out if eligible (Interviewer: Do you think about support at home?) You decide whether or not they are eligible and whether or not it will be of benefit for them is a separate issue.' (Oph8)

Some of the ophthalmologists (n=4) took account of a patient's practical visual needs when considering to offer certification.

'(If patients) highlight particular problems they are having…problems with seeing dials for thermostats, looking for instructions for things, could do with help regarding lighting even, if they ever talk about safety issues like gas fires or cookers or have burnt themselves I tend to worry more about safety…I think of offering low vision support as a package.' (Oph1)

Similar to the majority of the ophthalmologists, all three nurses interviewed stated that visual function was a primary factor in their decision whether to recommend certification.

Consultants appeared more likely to offer certification at the end of their treatment, they (n=5) often described how they regard certification as the 'final stage' in the management of the eye condition;

~~'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.' (Oph5)~~

~~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?'~~

~~Pat26: 'Absolutely, 100%.'~~

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 ~~most~~ by patients;

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

> ‘[social services]~~(SS)~~ 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 providing 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.' (Oph1)

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 ~~aim of this~~ current study ~~research was to~~ 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, [170], 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 blindness and sight impairment. [172]. 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, ~~the inconsistent decline in the number of certifications issued since the CVI was introduced in England in September 2005. Despite the ageing population and predicted increases in those with sight loss[10], there has been an inconsistent decline in both the number of certifications and number of registrations. Between 2010/11 and 2011/12 there was a 4% *increase* in the number of certifications in England[10] In contrast, between 2008/09 and 2009/10 there was a 5% *decrease* in the number of certifications.[11]~~

~~In addition the decline in new blind registrations at regional level reveals wide variations in the numbers registered.[12] The largest decline in new~~

registrations was observed in the East Midlands, where new blind registrations decreased by 52%, while the smallest decline was in the North East - only 10% (See Figure 1).[12] Even in small geographical areas the number of CVIs and associated registrations varied widely, e.g. in inner London new registrations fell by 41% whereas in outer London the decrease was 24%.[12] Reasons for the inconsistent declines in certifications and registrations are poorly understood.[13]

Interviews with 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 to those with untreatable disease.[184] The uncertainty of when to certify was also an issue for other eye conditions.[195] For example, certifying patients with atrophic AMD also presents significant timing difficulties.[2016] 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.

In addition, Ssome 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.[17]

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. ~~f the 46 patients interviewed, 20 stated they would have liked to have been offered certification earlier, to access support.~~

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 ~~H~~ recommends the CVI be sent to the local social services department "within five working days".[21~~18~~] Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within five 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.[22~~19~~] 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 ~~C&R~~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 practice and stories of both grateful and frustrated patients, thus a good certification process is achievable in every ~~ach~~ 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.[15] Any additional time needed for CVI discussion in clinic may not be readily available due to pressures on quantity (e.g. 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, a~~A~~s the research used qualitative methods, we were able to interview~~ed~~ a limited~~small~~ number of health and social care professionals. Further research is needed to examine

look at a wider range of departments over a longer period of time. Research is also needed to understand the impact of thenew Disability Living Allowance assessment policies and whether there is any pressure on ophthalmologists not to certify patients.

Discussion

The certification of vision impairment is inconsistently offered by ophthalmologists. The uncertainty of when to certify may be contributing to the decline in certifications. Many ophthalmologists regard certification as the end of a process instead of regarding it as a formal route to support.

Patients have both positive and negative experiences of certification. When the C&R processes 'work', patients access support within weeks, however often patients with vision impairment need and wish to access support before they are offered certification.

ECLOs play an important role in improving the C&R process, by making it more efficient and improving the process for consultants. Ophthalmologists may wish to consider their role beyond clinical care and utilise their skills better to offer the appropriate support to their patients. Certification changes patients' lives; ophthalmologists should acknowledge the significant role they play in helping patients access support and improve their quality of life.

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Competing interests:

None.

Acknowledgements:

Many thanks to the health professionals, representatives from social services and patients who participated in the interviews and took great courage in providing honest feedback on their experiences of the C&R process. Many thanks to the advisory group who provided guidance and advice.

References

1 RNIB. *Vision criteria for registration*. RNIB, 2014. http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/vision_criteria.aspx (Accessed 18 January 2014).
2 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-improving-outcomes-and-supporting-transparency (Accessed 18 January 2014).
3 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 January 2014)
4 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 January 2014)
5 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 January 2014)
6. 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 January 2014)
7. Malik ANJ, Bunce C, Wormald R, Suleman M, Stratton I, Muir Gray JA. Geographical variation in certification rates of blindness and sight impairment in

England, 2008–2009. *BMJOpen.* 2012; 2:e001496. doi:10.1136/bmjopen-2012-001496.
8 Britten N. Qualitative interviews in medical research. *BMJ* 1995; 311:251-3.
9 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 January 2014).
10 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.
11 McLean RJ, Windridge KC, Gottlob. Living with nystagmus: A qualitative study. *Br J Ophthalmol* 2012;96:981-986 doi:10.1136/bjophthalmol-2011-301183
12 Office for National Statistics. *Annual Mid-year Population Estimates, 2011 and 2012.* ONS, 2013. http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/stb---mid-2011---mid-2012-uk-population-estimates.html#tab-Mid-2011-and-mid-2012-UK-population-estimates- (Accessed 17 January 2014).
13 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 January 2014)
14 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.
15 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.
16 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.
17 Leamon S. *Number of adults and children certified with 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 January 2014).
18 Kotecha A, Fernandes S, Bunce C, Franks WA. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499
19 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8
20 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? *Eye* 2012;26:933-936.
21 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 January 2014).
22 Bunce C, Smyth L, Xing W, Zekite A (ND) *Research into drop in registrations of blind and partially sighted people.* (Supplied by first author, available from TB).

1 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 7 July 2013)

2 Department of Health. *Public Health Outcomes Framework 2013 to 2016 and technical updates.* DH, 2013. https://www.gov.uk/government/news/public-health-outcomes-framework-sets-out-desired-outcomes-and-supporting-transparency (accessed 7 July 2013).

3 Boyce T. *The Certification and Registration Processes: Stages, barriers and delays.* RNIB, 2012. http://www.rnib.org.uk/aboutus/Research/reports/otherresearch/Pages/certification_registration_processes.aspx (accessed 7 July 2013).

4 Britten N. Qualitative interviews in medical research. *BMJ* 1995; **311**:251-3.

4 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.

5 McLean RJ, Windridge KC, Gottlob. Living with nystagmus: A qualitative study. *Br J Ophthalmol* 2012;96:981-986 doi:10.1136/bjophthalmol-2011-301183

6 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.

7 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.

8 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.

9 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8

10 Leamon S. *Number of adults and children certified with 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 7 July 2013).

11 Leamon S. *Number of adults and children certified with sight impairment in England and Wales: April 2010-March 2011*. RNIB, 2012. http://www.rnib.org.uk/aboutus/Research/reports/otherresearch/Pages/sight_loss_statistics_report.aspx (accessed 7 July 2013)

12 Malik ANJ, Bunce C, Wormald R, Suleman M, Stratton I, Muir Gray JA. Geographical variation in certification rates of blindness and sight impairment in England, 2008–2009. *BMJOpen*. 2012; 2:e001496. doi:10.1136/bmjopen-2012-001496.

13 Lake R. *A review of information needs and practice relating to people with sensory impairments*. NHS Information Centre, 2010.

14 Kotecha A, Fernandes S, Bunce C, Franks WA. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499

15 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8

16 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? Eye 2012;26:933-936.

17 Department of Health. *Guidance published on registering a vision impairment as a disability*. http://www.dh.gov.uk/health/2013/01/cvi/ (accessed 7 July 2013).

18 Health and Social Care Information Centre. *People Registered as Blind and Partially Sighted - England, 2006, Triennial.* http://www.ic.nhs.uk/article/2021/Website

Search?productid=1885&q=blind+partially+sighted+2006&sort=Relevance&size=10&page=1&area=both#top (accessed 7 July 2013).

19 Bunce C, Smyth L, Xing W, Zekite A (ND) Research into drop in registrations of blind and partially sighted people. (Available from TB).

BMJ Open

Certification for vision impairment – Researching perceptions, processes and practicalities in health and social care professionals and patients

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004319.R2
Article Type:	Research
Date Submitted by the Author:	19-Mar-2014
Complete List of Authors:	Boyce, Tammy; Imperial College, Medicine Leamon, Shaun; Royal National Institute of Blind People, Slade, John; RNIB, Simkiss, Phillippa; RNIB, Judd Street rughani, sonal; RNIB, Judd Street Ghanchi, Faruque; Bradford Royal Infirmary, Ophthalmology
Primary Subject Heading:	Ophthalmology
Secondary Subject Heading:	Qualitative research, Evidence based practice, Health policy, Medical education and training, Public health
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, OPHTHALMOLOGY, PREVENTIVE MEDICINE, QUALITATIVE RESEARCH

Title:

Certification for vision impairment – Researching perceptions, processes and practicalities in health and social care professionals and patients

Keywords:

Blindness; Visually Impaired Persons; Certification of Vision Impairment; Professional-Patient Relations

Authors:

Dr T Boyce (Corresponding)
Department of Medicine
Imperial College
London

30 Victoria Park Rd East
Cardiff
CF5 1EH
<tboyce@imperial.ac.uk>

Mr Shaun Leamon
Royal National Institute of Blind People (RNIB)
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr J Slade
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Dr P Simkiss
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Ms S Rughani
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr Faruque Ghanchi

Bradford Teaching Hospitals NHS Foundation Trust
Duckworth Lane
Bradford
BD9 6RJ
01274 382386

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 is 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).

Conclusion

A better understanding of the certification and registration processes can help drive up standards of support and service provision for people who are severely sighted impaired or sight impaired. Better education and support is 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.

Article summary

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 including this group is needed to explore why these patients are declining certification.

Introduction (count 3863)

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose 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 this 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 Table 1 for an overview of criteria). Local Social Service Department (SSDs) then initiate the registration process upon 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 (e.g. 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.

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).[2] 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.[3] 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.[4] Certifications then decreased in 2009/2010 and 2010/2011, before rising to 23,616 in 2011/2012.[5] 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.[6]

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. [7]

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 semi-structured telephone interviews of clinical and social care providers and service users.[8] The study was

undertaken in three separate areas of England identified as having fluctuating rates of sight loss certification between 2006 and 2011[9]. NHS research ethics approval was secured for each hospital site. 43 health and social care professionals and 46 patients were interviewed by an experienced interviewer (See Table 2). The term 'patient' is used throughout the report 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 2). All ophthalmologists interviewed were consultants except one trainee registrar. Of the eleven consultants interviewed, two were qualified for less than two years; the remaining nine consultants were qualified for over ten 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,[10] 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.[11]

Fifteen per cent (n = 7) of patients classified themselves as Asian, seven per cent (n = 3) Black and the remainder White (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 fifty-seven per cent (n = 26) were women. Compared to national CVI figures, Black and Minority Ethnic patients were over represented and the gender characteristics of the sample were comparable with national demographics.[12, 13]

Interviews and Data Analysis

Semi-structured telephone interviews were conducted with individual participants at a time that suited the interviewees. Interviews lasted on average for 15 minutes; although some were substantially longer (patient interviews ranged from 8-40 minutes, interviews with health/social care professionals ranged from 6-50 minutes). 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; 3) and suggestions for improvement (See Box 1-3).

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

Box 1: Themes in ophthalmology/optometrist/nurse questions

CVI process Length from receiving CVI to sending to social services Purpose of CVI Improvements

Box 2: Themes in administrators/ ECLO questions

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

Box 3: Themes in patient questions

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.[14,15,16]

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 (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 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 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)

> '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 (i.e. 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 one 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 part-time 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.

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 providing 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, [17] 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. [7] 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 to those with untreatable disease.[18] The uncertainty of when to certify was also an issue for other eye conditions.[19] For example, certifying patients with atrophic AMD also presents significant timing difficulties.[20] 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".[21] Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within five 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.[22] 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 practice 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 (e.g. 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.

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Acknowledgements:

Many thanks to the health professionals, representatives from social services and patients who participated in the interviews and took great courage in providing honest feedback on their experiences of the C&R process. Many thanks to the advisory group who provided guidance and advice.

Funding statement

The Royal National Institute of Blind People funded this research. The funders contributed to the design of the research.

Contributorship Statement

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Competing interests:

None.

Data Sharing Statement

No additional data

References

1 RNIB. *Vision criteria for registration*. RNIB, 2014. http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/vision_criteria.aspx (Accessed 18 January 2014).

2 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-improving-outcomes-and-supporting-transparency (Accessed 18 January 2014).

3 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 January 2014)

4 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 January 2014)

5 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 January 2014)

6. 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 January 2014)

7. 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. doi:10.1136/bmjopen-2012-001496.

8 Britten N. Qualitative interviews in medical research. *BMJ* 1995; 311:251-3.

9 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 January 2014).

10 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.

11 McLean RJ, Windridge KC, Gottlob. Living with nystagmus: A qualitative study. *Br J Ophthalmol* 2012;96:981-986 doi:10.1136/bjophthalmol-2011-301183

12 Office for National Statistics. *Annual Mid-year Population Estimates, 2011 and 2012.* ONS, 2013. http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/stb---mid-2011---mid-2012-uk-population-estimates.html#tab-Mid-2011-and-mid-2012-UK-population-estimates- (Accessed 17 January 2014).

13 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 January 2014)

14 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.
15 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.
16 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.
17 Leamon S. *Number of adults and children certified with 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 January 2014).
18 Kotecha A, Fernandes S, Bunce C, Franks WA. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499
19 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8
20 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? *Eye* 2012;26:933-936.
21 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 January 2014).
22 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).

Table 1 Definitions of SI and SSI

To be registered as severely sight impaired (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 sight impaired (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.[1]

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

Table 2. 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

Title:

Certification for vision impairment – Researching perceptions, processes and practicalities in health and social care professionals and patients

Keywords:

Blindness; Visually Impaired Persons; Certification of Vision Impairment;

Professional-Patient Relations

Authors:

Dr T Boyce (Corresponding)
Department of Medicine
Imperial College
London

30 Victoria Park Rd East
Cardiff
CF5 1EH
<tboyce@imperial.ac.uk>

Mr Shaun Leamon
Royal National Institute of Blind People (RNIB)
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr J Slade
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Dr P Simkiss
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Ms S Rughani
RNIB
105 Judd Street
London
WC1H 9NE
020 7388 1266

Mr Faruque Ghanchi

Bradford Teaching Hospitals NHS Foundation Trust
Duckworth Lane
Bradford
BD9 6RJ
01274 382386

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 is 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).

Conclusion

A better understanding of the certification and registration processes can help drive up standards of support and service provision for people who are severely sighted impaired or sight impaired. Better education and support is 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.

Article summary

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 including this group is needed to explore why these patients are declining certification.

Funding statement

The Royal National Institute of Blind People funded this research. The funders contributed to the design of the research.

Introduction (count 3863)

The Certificate of Vision Impairment (CVI) was introduced in England in September 2005 and in Wales in April 2007. Its purpose 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 this 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 Table 1 for an overview of criteria). Local Social Service Department (SSDs) then initiate the registration process upon 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 (e.g. 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.

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).[2] 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.[3] 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.[4] Certifications then decreased in 2009/2010 and 2010/2011, before rising to 23,616 in 2011/2012.[5] 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.[6]

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. [7]

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 semi-structured telephone interviews of clinical and social care providers and service users.[8] The study was

undertaken in three separate areas of England identified as having fluctuating rates of sight loss certification between 2006 and 2011[9]. NHS research ethics approval was secured for each hospital site. 43 health and social care professionals and 46 patients were interviewed by an experienced interviewer (See Table 2). The term 'patient' is used throughout the report 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 2). All ophthalmologists interviewed were consultants except one trainee registrar. Of the eleven consultants interviewed, two were qualified for less than two years; the remaining nine consultants were qualified for over ten 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,[10] 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.[11]

Fifteen per cent (n = 7) of patients classified themselves as Asian, seven per cent (n = 3) Black and the remainder White (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 fifty-seven per cent (n = 26) were women. Compared to national CVI figures, Black and Minority Ethnic patients were over represented and the gender characteristics of the sample were comparable with national demographics.[12, 13]

Interviews and Data Analysis

Semi-structured telephone interviews were conducted with individual participants at a time that suited the interviewees. Interviews lasted on average for 15 minutes; although some were substantially longer (patient interviews ranged from 8-40 minutes, interviews with health/social care professionals ranged from 6-50 minutes). 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; 3) and suggestions for improvement (See Box 1-3).

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

Box 1: Themes in ophthalmology/optometrist/nurse questions

CVI process Length from receiving CVI to sending to social services Purpose of CVI Improvements

Box 2: Themes in administrators/ ECLO questions

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

Box 3: Themes in patient questions

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.[14,15,16]

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 (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 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 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)

> '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 (i.e. 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 one 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 part-time 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.

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 providing 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, [17] 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. [7] 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 to those with untreatable disease.[18] The uncertainty of when to certify was also an issue for other eye conditions.[19] For example, certifying patients with atrophic AMD also presents significant timing difficulties.[20] 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".[21] Across the three areas, interviews with hospital and social services staff and patients revealed that only very rarely were CVIs sent to SSDs within five 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.[22] 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 practice 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 (e.g. 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.

TB wrote the initial draft. All authors revised the initial draft, FG revised the subsequent drafts. TB and SL wrote the final draft. TB is the guarantor. All authors have full control of the content of the article.

Competing interests:

None.

Acknowledgements:

Many thanks to the health professionals, representatives from social services and patients who participated in the interviews and took great courage in providing honest feedback on their experiences of the C&R process. Many thanks to the advisory group who provided guidance and advice.

References

1 RNIB. *Vision criteria for registration*. RNIB, 2014. http://www.rnib.org.uk/livingwithsightloss/registeringsightloss/Pages/vision_criteria.aspx (Accessed 18 January 2014).
2 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-improving-outcomes-and-supporting-transparency (Accessed 18 January 2014).
3 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 January 2014)
4 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 January 2014)
5 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 January 2014)
6. 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 January 2014)
7. Malik ANJ, Bunce C, Wormald R, Suleman M, Stratton I, Muir Gray JA. Geographical variation in certification rates of blindness and sight impairment in England, 2008–2009. *BMJOpen.* 2012; 2:e001496. doi:10.1136/bmjopen-2012-001496.
8 Britten N. Qualitative interviews in medical research. *BMJ* 1995; 311:251-3.
9 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 January 2014).
10 McGuire LC. Remembering what the doctor said: Organization and adults - memory for medical information. *Exp. Aging Res* 1996;22:403–428.
11 McLean RJ, Windridge KC, Gottlob. Living with nystagmus: A qualitative study. *Br J Ophthalmol* 2012;96:981-986 doi:10.1136/bjophthalmol-2011-301183
12 Office for National Statistics. *Annual Mid-year Population Estimates, 2011 and 2012.* ONS, 2013.
http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/mid-2011-and-mid-2012/stb---mid-2011---mid-2012-uk-population-estimates.html#tab-Mid-2011-and-mid-2012-UK-population-estimates- (Accessed 17 January 2014).
13 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 January 2014)
14 Miles MB, Huberman AM. *Qualitative data analysis: An expanded sourcebook (Second Edition).* London: Sage Publications; 1994.
15 Morse JM, Field PA. *Qualitative research methods for health professionals (Second Edition).* London: Sage Publications; 1995.
16 Maxwell JA. *Qualitative research design. An interactive approach (Second edition).* London: Sage Publications; 2005.
17 Leamon S. *Number of adults and children certified with 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 January 2014).
18 Kotecha A, Fernandes S, Bunce C, Franks WA. Avoidable sight loss from glaucoma: is it unavoidable? *Br J Ophthalmol* 2012;96:816e820. doi:10.1136/bjophthalmol-2012-301499
19 Barry RJ, Murray PI. Unregistered visual impairment: is registration a failing system? *Br J Ophthalmol* 2005;89:995e8
20 Rostron E, McKibbin M. Visual impairment certification secondary to ARMD in Leeds, 2005–2010: is the incidence falling? *Eye* 2012;26:933-936.
21 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 January 2014).
22 Bunce C, Smyth L, Xing W, Zekite A (ND) *Research into drop in registrations of blind and partially sighted people.* (Supplied by first author, available from TB).