# The Certification and Registration Processes: Stages, barriers and delays

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## 1. Introduction

Certification and registration (C&R) bridges health and social care and involves many stakeholders including; Public Health, Primary Care, Social Care and Local Authorities. The Public Health Outcomes Framework has introduced an indicator for preventable sight loss, likely to be based on CVI figures. RNIB is concerned that people are certified and registered when they are eligible to promote early intervention. We commissioned Dr Tammy Boyce to document C&R processes from the perspective of professionals and patients; examine the relationship between health and social care and the role of these professionals in C&R; understand related barriers and enablers to C&R.

The Certificate of Vision Impairment (CVI) formally certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). The purpose of the CVI is to provide a reliable route for someone with sight loss to formally be brought to the attention of social care. In addition epidemiological analysis of CVI data provides information on the prevalence of sight loss. Registration as blind or partially sighted is provided by Social Service Departments (SSDs) and these registers its purpose of these registers is to help local authorities plan and provide services for people who have sight problems. Registration is a voluntary choice.

A literature review details the benefits of certification and registration. It highlights evidence that the population with sight loss is growing yet there has been a decline in both C&R. This decline has been inconsistent across the UK and whilst this report focuses on the situation in England, its findings are relevant to the wider UK context.

## 2. Method

Patients and professionals (hospital and social services staff involved in certification and registration) in three urban areas of England were interviewed by telephone. A total of 46 patients who had been certified in the past 12 months and 43 professionals (e.g. 12 consultant ophthalmologists, 4 eye clinic liaison officers, 8 rehabilitation officers) took part.

## 3. Key Messages from the research

### 3.1 Certification is life changing for patients

At the time of being certified many patients spoke of feeling ‘shocked’ and ‘overwhelmed.’ This did not differ in patients who lost their sight gradually compared to those who lost their sight more quickly, nor did reaction differ according to age or gender.

‘Vision started to deteriorate and I put it down to the fact I wasn’t sleeping... (Being told she was eligible to be certified) floored me completely. I hadn’t even considered myself as having a visual impairment, let alone a severe visual impairment.’ (Patient)

Being certified and registered is life changing for many patients and they described the help they receive at this time as substantially improving their lives.

Interviewer: 'Has registration helped you?

Patient: 'Absolutely, 100 per cent.'

When the C&R processes ‘work’, patients access support within weeks. However for many patients the C&R processes are drawn out, complicated and fraught with frustrations.

### 3.2 The five stages of certification and registration

There are five distinct stages to the C&R processes.

1. Certification Stage 1: Deciding it's right to certify
2. Certification Stage 2: Completing the CVI
3. Certification Stage 3: Sending CVI to SSDs, Moorfields Eye Hospital, Patient and GP
4. Registration Stage 1: Initial SSD assessment
5. Registration Stage 2: Second (full) SSD assessment

Numerous people are involved in completing the five stages in the certification and registration processes. Each of these professionals – ophthalmologists, registrars, optometrists, medical secretaries, CVI administrators, Eye Clinic Liaison Officers (ECLOs), Rehabilitation Officers, social services managers and administrators – have the potential to create barriers and delays or to improve the C&R processes.

### 3.3 Barriers leading to variation in certification and registration

The key factors in the C&R processes that may reduce the number of CVIs and registrations issued are at:

* Certification Stage 1: Failing to certify at the appropriate time or at all
* Certification Stages 2/3: Failing to complete the CVI and/or failing to send to SSDs
* Registration Stage 1: Failing to register patients upon receipt of CVI

Certification Stages 1-3 differed in each of the three areas and each consultant’s practice also differed within hospitals. Registration Stages 1 and 2, completed by SSDs, differed in each of the three areas in terms of the length of time it took to contact patients, but the actual services they offered were fairly similar. These differences contributed to the variation in the quality of services offered.

The main barriers to being certified are:

#### 3.3.1 The uncertainty of when to certify on the part of the ophthalmologist, particularly for people with long term conditions such as AMD, glaucoma or diabetic retinopathy.

For some patients it is clearly evident when their eye sight has reached the point to be certified but for many patients deciding when to certify is more ambiguous. Vision can fluctuate so deciding whether or not a patient is eligible to be certified is not a simple formula to follow.

People with long term conditions such as glaucoma or diabetic retinopathy will often require long term support from low vision services and SSDs (including rehabilitation). Ophthalmologists found it difficult to ascertain when it is appropriate to certify these patients. Many patients with age related macular degeneration (AMD), the cause of just over half of all certifications in England and Wales, will be on anti-VEGF treatments to improve or stabilise vision. So it can be difficult to make a judgement about eligibility for certification.

Consultants may expect treatment for AMD should be given time to work before certification is offered.

The report recommends that more guidance on when to offer certification is needed.

#### 3.3.2 External pressures to reduce certification rates.

Two consultants at different hospitals spoke of the **pressure not to certify patients**. They felt that high rates of certification may suggest that they are not adequately treating their patients and are somehow ‘failing’. The report recommends that audits of certification levels at hospitals are used to demonstrate that high certification rates do not signify ‘bad/poor’ service but are indications that health professionals are providing timely support to their patients.

#### 3.3.3 Clinicians regarding certification as end of process, not a route to services and therefore failing to offer certification when patients are eligible.

Part of the reason why consultants may delay certifying patients is that they regard certification as the end of a clinical process: clinicians wait to certify patients until they think they cannot offer any further medical treatments. Most consultants stated that they, and their colleagues, regard certification as the ‘final stage’ in treatment. **Patients do not regard being certified as the end of a clinical process** - instead it is often the point when they begin to accept the severity of their sight loss. The reality is that there may be little left to do medically but access to practical and emotional support can offer much more to change and improve a patient’s quality of life.

#### 3.3.4 Poor awareness of the benefits of being certified and registered leading to failure to offer certification as clinicians saw no need/little value to patients.

Many health professionals were poorly informed about the purpose and benefits of C&R. 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. It was more common for ophthalmologists and optometrists to admit they had little knowledge of what being C&R offered and often had negative views of being certified as a result.

If health professionals are poorly informed it is unclear how they are able to advise patients about the benefits of being C&R. The risk is that they will provide no information or incorrect information and confuse patients.

The implications of not being aware of the details of the C&R processes or what they impact on influences who is offered certification and when. For example a small number of consultants openly stated they did not see the point in certifying older people who already received services stating that as older people already received a free television license there was little point in registering older people.

Some ophthalmologists depended on the ECLO to explain the C&R processes and benefits. All health professionals stated they know little about patients’ experiences with SSDs or of being registered as they received little feedback from patients. The report suggests that there may be a risk of consultants’ absolving themselves of being aware of the benefits of being C&R. This could result in them being unclear on how to advise patients or support them with decision making in the appointment as they have little information about the benefits of being C&R.

#### 3.3.5 Incorrect assumptions about patients’ views and believing patients do not ‘need’ to be certified.

While more health professionals stated patients did not decline the offer to be certified a small number said that patients’ attitudes to being certified and registered acted as a potential barrier / delay in the C&R processes was. These health professionals stated patients often declined the offer to be certified and some argued they declined because of the stigma of being certified. When asked if they encourage or discourage patients – **not one interviewee said they discouraged patients from being certified**. In fact many did encourage those who hesitated, particularly ECLOs.

However, in interviews **not one patient alluded to problems with the labels or felt stigma** associated with being certified or registered.

SSDs stated patients were unlikely to decline registration, as explained in Registration Stage 1. Interviews with SSDs found stigma was only identified as an issue by two interviewees. One rehabilitation officer stated young people were concerned the effect of being registered on job prospects whilst another said people ‘don’t want to be labelled as disabled, like going on disability register, don’t feel sight is bad enough to go on register.’

#### 3.3.6 Lack of clarity regarding payment for signing the CVI.

When asked directly if the payment affected the numbers certified, most ophthalmologists stated it did not factor into their decision to certify a patient. The report noted that the areas studied may have affected the findings regarding payment as in two of the areas studied, many consultants (but not all) donated their certification fees to support the ECLO or a local vision charity.

This issue is likely to become more complicated in England as Primary Care Trusts are replaced with Clinical Commissioning Groups which may lead to wider variation in payments for certifications and the report calls for clarification on payments for certification.

### 3.4 Additional delays can affect the health of patients

Additional delays were identified as

* The length of time for consultants to complete CVIs
* Sending incomplete CVIs to SSDs
* The length of time for CVIs to be sent to SSDs.

These delays do not necessarily affect the numbers certified or registered, but can substantially affect a patient’s life and their physical and mental health.

### 3.5 The effect of new treatments on certification numbers is not a factor

A small number of consultants suggested the reason for the decline in certifications is the widening access to the NHS Diabetic Eye Screening Programme or sight saving treatments as examples.

The report presents a number of reasons why access to screening and treatments are not the likely reason for the decline in certifications / registrations.

The NHS Diabetic Eye Screening Programme (DESP), which aims to reduce the reduce sight loss through early detection and appropriate treatment of diabetic retinopathy, was introduced over ten years ago. Its effects on numbers certified and registered are poorly understood. The effect of the DESP may vary as the percentage of the diabetic population receiving screening for diabetic retinopathy ranged from 7.4% to 91.8% (12-fold). The level of variation in the uptake of screening has been identified as ‘of great concern’ in the literature.

Consultant Ophthalmologists often highlight reduction in wet AMD due to new treatment as a specific reason for drop in certifications. The report notes that the largest drop in certifications occurred before the introduction of anti-VEGF drugs. Lucentis treatment was licensed by NICE in 2008 but the largest drop in SSI and SI registrations occurred between 2003 - 06.

The report concludes that if new treatments were reducing the need for certifications, the decline would be similar across the UK. However, the decline in certifications varies across the UK and in some areas certifications are increasing. The report acknowledges that this variation in outcomes may be due to variations in treatment and highlights the need for further research.

## 4. In summary

In an era where the NHS is looking to decrease variation and improve quality and patient experiences, better understanding the C&R processes can help to drive up standards of support and provision for people who are blind or partially sighted. The research gives the following general recommendations:

* Educate ophthalmologists of the importance of timely referral for rehabilitative support and certification and registration.
* There is a need for good practice guidelines for all stakeholders in the C&R processes. Guidelines should include length of time to complete each of the five C&R Stages. Patients should be made aware of these guidelines and the recommended length of time to complete each stage.
* Formal relationships between ophthalmology departments, low vision clinics and local social services should be established to improve understanding of the benefits of registration.
* Many patients and health professionals found ECLOs or a dedicated CVI team extremely helpful in completing the CVI and improving the C&R processes. Indeed when asked how to improve the C&R process, both health professionals and patients suggested more ECLOs and with more consistent hours.
* In light of the public health indicator for preventable sight loss, it should be made mandatory to send each CVI to the certification office at Moorfields to accurately reflect the number of certifications in each area.
* The introduction of new PH indicator must not penalise consultants. An increase in the numbers certified should not necessarily be regarded as poor consultant practice.
* Some consultants on certain contracts are paid to complete CVIs, others are not. In order to remove the effect of payment on the C&R processes, there should be a consistent payment for all consultants.
* Patients should be provided with information prior to the first Certification Stage.
* The implications of registration being ‘opt out’ rather than ‘opt in’ should be examined: as so few patients refuse registration, create a nudge to reduce the likelihood of the C&R process taking longer: make registration opt out rather than opt in.
* An Electronic Certificate of Visual Impairment should be implemented to save time at Certification stage 2 and 3 and thus promote speedier referral to local services.

Specific recommendations are also given for different stakeholder groups: clinicians, third sector, social service departments, Royal College of Ophthalmologists, Department of Health and Association of Directors of Social Services (ADASS).

## 5. Further information

The full report can be downloaded from the research section of the RNIB website: [www.rnib.org.uk/research](http://www.rnib.org.uk/research).

The reference for the report is:

Boyce, T (2012) **The Certification and Registration Processes: Stages, barriers and delays**. RNIB.

For further information please contact RNIB Evidence and Service Impact by emailing [research@rnib.org.uk](mailto:research@rnib.org.uk).

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