This publication summarises findings from research conducted by Barbara Ryan and Tom Margrain, School of Optometry and Vision Sciences, Cardiff University, and Angela Reidy and Darwin Minassian.

Thomas Pocklington Trust commissioned a study to look at those using the community-based low vision service. Data collected on adults using the Welsh Low Vision Service (WLVS) was extracted from the service administration database and prepared and analysed by two epidemiologists.

- Information was analysed on 5817 adults.
- About 90% were over pensionable age and 66% were women.
- A large proportion of those whose vision was much better than 6/60 (i.e. better than the level at which people can be registered as having sight impairment in the UK by visual acuity alone) were not registered but were receiving NHS low vision rehabilitation services and social services support.
- Nearly 70% of those using the WLVS had visual acuity better than 6/60 and about 60% were not registered.
- Age was found to be a significant barrier to registration and the older the person the less likely they were to be registered.

As many other studies have only recruited people who were registered as sight impaired, these research findings provide useful information for policy makers, service providers and researchers concerned with improving the lives of people with sight loss. In particular, they question the value of current UK registration criteria because these appear to have little relevance in determining the need for provision of modern statutory rehabilitation services for people with sight impairment.
Introduction

Until now, routine information has not been employed to report on the use of services or the social circumstances or the characteristics of people with untreatable sight loss.

In Wales, statutory funded rehabilitation services for people with a visual impairment are provided in two settings: NHS funded low vision services and local authority funded rehabilitation services. These two services should work together to provide seamless support for people losing their sight. About half of the people who use NHS funded low vision services in Wales use hospital services and half use the Welsh Low Vision Service (WLVS).

The WLVS is located in community-based optometric practices and direct referrals are accepted, following a recent eye examination, from a range of professionals and from individuals themselves. Therefore, the WLVS is an ‘open access’ rehabilitation service for people with sight loss.

When the WLVS was developed, an administrative database was established. Since it was set up in 2004, information about a large number of people with sight loss has accrued which has the facility to become a research resource. This resource, while not being a methodically derived sample or a total population, has the potential to cover a large number of people in Wales with sight loss. The opportunity is available for researchers to use this database to provide quantitative information about the characteristics of those accessing low vision services.

Methods used in the study

Data Collection

Practitioners accredited to provide the WLVS were supplied with standard record cards, which included information about the person, what they could see and what services they had used. Practitioners asked the person to sign to consent to use of the information for audit and research purposes, but they were free to withhold consent if they wished. Following a low vision assessment, the practitioners were required to fax the record cards (via a secure fax) to the central NHS administration team in Carmarthenshire LHB. Information from patients’ record cards was incorporated into a computer database. All procedures adhered to the tenets of the Declaration of Helsinki and ethical approval was obtained from the All Wales Research Ethical Committee.
Data Extraction
Data collected between April 2004 and April 2007 were extracted from the administration database and analysed by two epidemiologists. Neither of the epidemiologists was involved in the development of the service or the database, i.e. this evaluation was independent.

Only data meeting the following criteria were extracted for analysis:
- Signed consent had been obtained
- The visit had to be the first low vision assessment visit
- Patients were aged 18 or over, i.e. children were excluded.

Variables identified for analysis included:
- Gender
- Date of birth
- Date record completed
- Previous consultations: Ophthalmology, Low Vision
- Living arrangement: alone; with partner/spouse; with other relatives; sheltered accommodation; residential care
- Registration status: Registered Blind; Registered Partially Sighted; Not Registered; Status not known
- Services received prior to assessment: social services; voluntary sector; education; employment; other; none
- Visual Acuity: Best Binocular Distance VA (Snellen acuity, Hand Movements or Perception of Light)
- Services referred to following assessment
- Patient agrees to audit and research
- Patient’s signature confirmed

Data Analysis
Data were analysed using SPSS and STATA. Most of the analysis involved simple cross-tabulations, and assessment of relationships using significance tests based on chi square or t-tests, as appropriate. In some instances, however, logistic regression was used to clarify some of the more complex relationships that were apparent in the cross-tabulations.
Findings

Data from 5830 records were available for analysis:

- Overall just less than 90% were over pensionable age (>65 years)
- About 45% lived alone
- About 85% had visual acuity worse than 6/12, about 30% had visual acuity of 6/60 or worse and 10% had a visual acuity of worse than 3/60
- Almost 70% of those attending had age-related macular degeneration

About registration and the services received:

- Approximately 70% of people who accessed the service did not meet the visual acuity guideline criteria for registration (6/60). This suggests that people need to access services before their acuity drops to registerable levels.
- Just over half the sample indicated they had not received any services before their low vision visit.
- Of those who had received one or more of the support services:
  - just over 41% reported receiving services from social services and
  - just over 11% from the voluntary sector.
- Just over half reported having had a previous ophthalmological consultation and about a fifth had had a previous low vision consultation. Younger people were more likely to have had a consultation and men were more likely to have had a low vision consultation than women.
- Less than 40% of those attending reported that they were registered as either ‘blind’ or ‘partially sighted’.
- Age was strongly related to registration status at first assessment; the older age groups being significantly less likely to have reported being registered compared to the youngest age group.
- A significantly higher proportion of those reported as being registered were patients living with a partner / spouse and those living in sheltered accommodation.
- Just under 10% of those with VA 6/60 or worse:
  - reported that they were not registered
  - reported that they had not been in touch with any other support services before
  - were not referred to any services after their low vision assessment.
Following assessment, about a quarter of those assessed in the WLVS were referred to one or more other services. People were most likely to be referred to statutory services, e.g. social services and/or ophthalmologists for consultation and/or registration.

About the database
The overall organisation of the database and the facilities it provides are indicative of high quality technical expertise. This initial analysis suggests that, with some adaptations, the database could be developed into a research resource, providing useful information for policy makers, service providers and researchers concerned with improving the lives of people with sight loss. In particular, it could be used to provide samples for research projects and to investigate how a person’s service use and vision change over time.

Conclusions
This study found that with some adaptations, the database could be developed into a research resource, providing useful information for policy makers, service providers and researchers concerned with improving the lives of people with sight loss.

These findings question the value of current registration criteria as these criteria appear to have little relevance in determining the need for provision of modern statutory rehabilitation services for people with sight loss.
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How to obtain further information

A short report, in the form of an ‘Occasional Paper’ entitled All Wales Visual Impairment Database by Barbara Ryan and Tom Margrain of the Cardiff University School of Optometry and Vision Sciences, and Angela Reidy and Darwin Minnassian, is available from:

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Horticultural Place  
London W4 4JQ

Telephone: 020 8995 0880  
Email: info@pocklington-trust.org.uk  
Web: www.pocklington-trust.org.uk
Background on Pocklington

Thomas Pocklington Trust is a leading provider of housing, care and support services for people with sight loss in the UK. Each year we also fund a programme of social and public health research and development projects.

Pocklington’s operations offer a range of sheltered and supported housing, residential care, respite care, day services, resource centres and volunteer-based community support services.

We strive to improve continuously the quality standards in our operational centres to meet the changing needs and expectations of our current and future service users. We are proud to be an Investor in People and a Positive about Disability organisation.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss by improving social inclusion, independence and quality of life, and improving and developing service outcomes as well as focusing on public health issues.

In this publication, the terms ‘visually impaired people’, ‘blind and partially sighted people’ and ‘people with sight loss’ all refer to people who are blind or who have partial sight.