Benefits case study

‘Registered blind and partially sighted’ (2011) publication

Improving services for people with visual impairment

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Date: 11/11/2014
Version: 1.1
Version History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date</th>
<th>Summary of changes</th>
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<tbody>
<tr>
<td>1.0</td>
<td>06/11/2014</td>
<td>First release.</td>
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<td>1.1</td>
<td>11/11/2014</td>
<td>Incremented to v1.1 to rectify a date error on the front cover. No other change has been made to the document.</td>
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1 Purpose of case study

Triennially since 2006, the Health and Social Care Information Centre (HSCIC) has produced the ‘Registered Blind and Partially Sighted People’ publication. The purpose of this case study is to describe how charities and services, such as the Royal National Institute of Blind People (RNIB), the Guide Dogs for the Blind Association, the Thomas Pocklington Trust and the Certifications Office, and local authorities have used the 2011 ‘Registered Blind and Partially Sighted People’ publication to contribute to outcomes and benefits in visual impairment services. The 2014 ‘Registered Blind and Partially Sighted People’ publication was released in September 2014, but is out of scope for this case study.

The ‘Registered Blind and Partially Sighted People’ allows stakeholders to carry out activities and implement process changes. It is these activities and process changes that contribute to the outcomes and benefits stated in sections six and seven. This case study is highlighting what role the publication played in contributing to these outcomes and benefits.

2 ‘Registered Blind and Partially Sighted People’ publication

2.1 Data collection process

The ‘Registered Blind and Partially Sighted People’ publication contains statistics on persons registered as blind or partially sighted with councils and adult social services responsibilities (CASSRs) on 31 March 2011. The publication is the only resource that presents data at a national and local authority level for this group of people.

The data presented in the publication is based on the SSDA 902 form, which local authorities submit electronically to HSCIC. Under Section 29, part 4(g) of the National Assistance Act 1948 and Section 77, part 1 of the Care Act 2014, local authorities are required to maintain a register of severely sight impaired (SSI) and sight impaired (SI) adults resident in their area. Local authorities base their electronic submissions to HSCIC on these registers (although the submissions contain data for people of all ages).

The local authority registration process commences with the Certificate of Vision Impairments (CVIs), which consultant ophthalmologists (eye specialists) complete when certifying patients as SSI (i.e. blind) or SI (i.e. partially sighted). The original CVIs are

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1 The data set was supplied by HSCIC’s predecessor organisation, NHS Information Centre (NHS IC)
2 The 2009 publication was bought forward by a year to 2008, so there was only a 2 year gap between the 2006 and 2008 publications. The three year cycle re-continued from 2008.
3 For the duration of this case study, all uses of “local authorities” refer to CASSRs.
retained by the certifying hospitals, but copies are shared with four entities, two of these being:

- Certifications Office for epidemiological analysis. The Certifications Office operates under the auspices of the Royal College of Ophthalmologists and is based at Moorfields Eye Hospital NHS Foundation Trust,

- The patient’s local authority for registration and service needs assessment.

For the duration of this case study, all uses of “local authorities” refer to CASSRs.

2.2 Key findings

The key findings highlighted in the 2011 ‘Registered Blind and Partially Sighted People’ publication are as follows:

- 147,800 registered blind as at 31 March 2011, a decrease of 5,200 (3%) from 2008
  - 9,100 new entries on the local authority register of SI and SSI in 2010/11
  - 64% of people registered blind are 75 and over, as at 31 March 2011.

- 151,000 registered partially sighted as at 31 March 2011, a decrease of 5,300 (3%) from 2008
  - 11,800 new entries on the local authority register of SI and SSI in 2010/11
  - 66% of people registered partially sighted are 75 or over, as at 31 March 2011.

For the duration of this case study, all uses of “registration(s)” and “registration data” will refer to the publication’s local authority SI and SSI registration data.

3 ‘Registered Blind and Partially Sighted People’ publication history

The responsibility for producing the ‘Registered Blind and Partially Sighted People’ publication initially lay with Department of Health (DH), but, at the inception of the NHS Information Centre (NHS IC) in 2005, this responsibility transferred to the HSCIC.

In 2008, HSCIC consulted with stakeholders to investigate whether the publication served a purpose in the planning and delivery of visual impairment services. All key stakeholders responded positively, so the HSCIC has continued releasing the publication triennially.

4 Objectives of the ‘Registered Blind and Partially Sighted People’ publication

The objectives of the ‘Registered Blind and Partially Sighted People’ publication are to enable:

- government departments to monitor the impact of social care policy on blind and partially sighted people, ensuring they have access to the right services and are not negatively impacted as a consequence of the introduction of policy

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iv DH was producing the publication triennially since at least 1982.
• policy makers and commissioners to understand the needs of local and national populations

• service providers and charities to effectively plan the service needs for registered blind and partially sighted people

• local authorities to benchmark against peers.

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**Quote**

"The HSCIC report is the only centrally funded publication on numbers of people with registrable sight impairment in England. Anyone who wanted information regarding levels of sight loss in England would have used this publication and without this publication, it is not clear how central planning of provision of services to those with sight impairment could have happened." Catey Bunce, Principal statistician, Moorfields Eye Hospital NHS Foundation Trust (2014)

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**5 ‘Registered Blind and Partially Sighted People’ publication uses**

**5.1 Certifications Office**

The Certifications Office used the ‘Registered Blind and Partially Sighted People’ publication to assess for each local authority in England the variance between 2010/11 registrations and 2010/11 CVIs. This analysis served two purposes:

1. Supplement Public Health Outcomes Framework 2013-16 indicator 4.12 (preventable sight loss)\(^7\) – the Certifications Office is responsible for submitting CVI figures to Public Health England (PHE), to feed into indicator 4.12. As part of this duty, the Certifications Office provided written commentary explaining how the 2010/11 CVI data compared to 2010/11 registrations.

2. Establish whether variances are due to local systematic failures - generally, the number of CVIs reported to the Certifications Office is expected to be higher than the number of registrations, due to reasons such as patients refusing local authority registrations. Consequently an exact match is never expected, however, significant variances (i.e. variances of 10% or more) are cause for concern. In 2010/11, 30 authorities had significantly more registrations than CVIs and 53 authorities had certifications significantly higher than registrations.

All significant variances were reported by the Certifications Office to the Certification of Vision Impairment Committee (CVIC) and CVIC representatives subsequently investigated the reasons for the variances. Where variances related to operational issues, this, in some cases, resulted in process changes. For example:

• one hospital in north of England only sent 24 CVIs to Moorfields in 2010/11, but the corresponding local authority had more than 200 registrations. The investigation highlighted that this variance was as a result of the local hospital not sending CVIs to Certifications Office. The hospital has now refined its process and, as a result, is believed to be sending all CVIs to the Certifications Office.

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**Quote**
5.2 RNIB

RNIB “is a charity and membership body of and for blind people and those with sight problems”8. It provides practical and emotional support, information, advice, products and services and is a leading voice nationally and internationally with and on behalf of blind and partially sighted people. RNIB has used the ‘Registered Blind and Partially Sighted People’ publication to inform various activities, some of which are noted below.

5.2.1 Sight Loss Data Tool (SLDT)

The publication is used by RNIB to feed into their SLDT. The tool contains data from various sources, including, among others, the ‘Registered Blind and Partially Sighted People’ publication, Hospital Episode Statistics and Office of National Statistics.

The tool provides information at a local level about people with, and at risk of, sight loss. It seeks to ensure that the needs of these people are taken into account by service providers when planning services and producing related documentation, such as the Joint Strategic Needs Assessments (JSNAs).9

5.2.2 Optimeyes

RNIB and partners have submitted a funding bid for £400k to Big Lottery for the Optimeyes project. The project seeks to enable older people, especially those with or at risk of sight loss, to better manage the changes they encounter in later life and to reduce isolation. Optimeyes has used the ‘Registered Blind and Partially Sighted People’ publication to analyse, for six local charities, the differences in numbers between local authority registrations and local charity service users. The purpose of this is to set out in the bid what proportion of people is unsupported by local charities, and, what proportion will be targeted for service provision. An example of where a variation was identified was:

- one charity in the Eastern region was in contact with approximately 1,000 people affected by sight loss, but the local authority register of SI and SSI showed that there were 3,870 people (registered blind and partially sighted)

The predecessor project, Older People Taking Control (OPTiC), which operated between 2012 and 2014, delivered benefits for people with sight loss. For example, it offered eye health advice and screening to 35,760 people and support services to 407 people.10 Although the ‘Registered Blind and Partially Sighted People’ publication was not used to aid the OPTiC project, it is expected that the same types of benefits can be realised and quantified for the Optimeyes project.

5.2.3 Eye Clinic Liaison officers (ECLOs)

ECLOs are based at eye clinics (hospitals) and provide emotional and practical support to people with sight loss, including those certified as SSI or SI. At present, RNIB estimates that funding through NHS and local authorities is only available for around a quarter of the ECLOs needed to support people affected by sight impairment. To address this service
provision gap, RNIB is working with partners to present funding proposals to various bodies. For example:

- RNIB, Action for Blind People, Sheffield Royal Society for the Blind and Royal Hallamshire Hospital are working in collaboration to present funding proposals to various bodies, including clinical commissioning groups (CCGs) and the local authority.

Within these proposals, the ‘Registered Blind and Partially Sighted People’ publication and CVI data are used to estimate the spread of likely minimum demand for ECLOs across local authority areas and hospitals and, if relevant, how strong the local need is for an ECLO.

**Quote**

"At RNIB we know that registration as blind or partially sighted can be life changing for people. It can be overwhelming and yet an empowering experience if people are given choice and control in their own care. The register is a vital tool in our campaigning work - we use it to present a picture of local and national need to service providers and policy makers. We pay special attention to the newly registered population as this shows us which local authorities could take action to provide early access to information and advice, rehabilitation, and aids and adaptations." Dr Philippa Simkiss, Head of evidence and service impact, RNIB (2014)

### 5.3 Guide Dogs

The Guide Dogs for the Blind Association (“Guide Dogs”) is a charitable organisation that provides a range of mobility services to blind and partially sighted people, such as guide dogs, buddy dog service and My Guide partnerships. It aims to enable “more people who are blind and partially sighted to get out and about on their own terms, and offering them a broader range of services”\(^{11}\).

Guide Dogs uses the ‘Registered Blind and Partially Sighted People’ publication to:

- inform service needs - the publication is one of the key sources of information that Guide Dogs uses to monitor the likely future demand for their range of mobility services, such as guide dogs and long cane mobility training.

- focus services where they are most needed – Guide Dogs used the publication’s local authority-level data to establish potential visual impairment service needs within local authority areas. For instance, Guide Dogs established which local authority areas are more likely to require guide dogs, rather than My Guide partnerships, and vice versa.

- increase awareness of the strong association between old age and visual impairment – the ‘Registered Blind and Partially Sighted People’ publication states that more than 70% of cases of visual impairment are in people 65 and over. Guide Dogs has assessed that services for older people do not specifically take into account sensory impairment, and, as a consequence, some of their visual impairment needs are unmet. To address this issue, Guide Dogs draws upon authoritative data, such as the ‘Registered Blind and Partially Sighted People’ publication, to engage with local organisations, in order to highlight this issue. For example:
  - partners in the Ageing Better\(^{12}\) Big Lottery Fund application for Birmingham (which includes Guide Dogs) incorporated registration data to highlight the high
prevalence rates of sight loss in older people. The project has secured £6m, although not all will be spent on improving services for older people with sight loss.

Guide Dogs has also shared sight loss data with various local Health and Wellbeing Boards, in order that sight loss issues are better reflected in local plans.

**Quote**

“Whilst prevalence data are useful, we particularly value the triennial registration data, particularly those pertaining to new registrations as the information gives us and our sector partners a very clear idea of the numbers and types of people who are ‘in the system’. It is essential to have such robust data if we are to have any chance of influencing local health and wellbeing strategies with regard to the discrete needs of those with sight loss. The data also contribute to our own service delivery plans.” Carl Freeman, Policy Manager, Guide Dogs (2014)

5.4 **UK Vision Strategy refresh working group**

The UK Vision Strategy is supported by a wide alliance of eye health and sight loss organisations. It was launched in 2008 and refreshed in 2013 as UK Vision Strategy 2013-2018 – Setting the direction for eye health and sight loss services. The refreshed strategy links to the ‘Registered Blind and Partially Sighted People’ publication in two ways:

1. the publication informed outcome 2 of the strategy, which sets out that “Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all”.

2. local authority registration for people diagnosed with SI and SSI is promoted through appendix D (of the strategy), “You and your vision: a charter for eye care and sight loss services”.

5.5 **Local vision strategies**

On the back of the UK Vision Strategy 2013-2018, the London Visual Impairment Forum (LVIF) and the Thomas Pocklington Trust have collaboratively worked with a number of London-based CCGs, local authorities and local sight loss charities to develop local vision strategies. The strategies were informed by the ‘Registered Blind and Partially Sighted People’ publication and RNIB’s SLDT, through data items such as the 2011 local sight loss prevalence and the projected increase in local sight loss prevalence by 2020. Example strategies include Havering Vision Strategy and Newham Vision Strategy. There has been insufficient lead time to establish what improvements have resulted from these strategies; however, there are examples where the vision strategies are being, or have been, used to improve the service provision for people affected by sight loss. For example:

- through the use of various information sources, including the local vision strategy, Barnet Council will be presenting the case for an ECLO to Barnet’s Health and Wellbeing Board for funding for a post at the Royal Free London NHS Foundation Trust. The post will cover the eye-clinics of Royal Free Hospital and Barnet Hospital.
Thomas Pocklington Trust has developed two cluster bodies in East and South East London, each with dedicated funding and strategies, to deliver improvements in the quality and availability of visual impairment services. East London Vision\(^{18}\), which was the first cluster to be established, was done so in 2013 and South East London Vision\(^{19}\) was established in April 2014.

**Quote**

"The data provided by the triennial HSCIC Registered Blind and Partially Sighted publication has been vital in our work, giving us a clear picture of local prevalence. Without this reliable evidence we would not have been able to engage as effectively with directors and senior commissioners at a local level to discuss the issues facing people with sight loss. Working with these stakeholders we have developed local vision strategies, which will deliver much needed targeted improvements for the local population, with this data at the heart of the decision making.” Phil Ambler, Policy Director, Thomas Pocklington Trust (2014)

### 5.6 Local JSNAs

Local authorities and local health and wellbeing boards have used the SLDT, ‘Registered Blind and Partially Sighted People’ publication and local vision strategies to inform the development of JSNAs. JSNAs analyse the health needs of local populations to inform and guide commissioning activities within local authority areas.\(^{20}\) Two examples of JSNAs that reference the ‘Registered Blind and Partially Sighted People’ publication and RNIB’s SLDT are Milton Keynes\(^{21}\) and Enfield\(^{22}\) JSNAs.

### 5.7 Ophthalmic research

Two research papers have cited the ‘Registered Blind and Partially Sighted People’ publication. These are as follows:

- *Childhood visual impairment in England: a rising trend*\(^{23}\)
- *Certification for vision impairment; researching perceptions, processes and practicalities in health and social care professionals and patients*\(^{24}\)

### 6 Improved outcomes in the provision and delivery of visual impairment services

The use of the ‘Registered Blind and Partially Sighted People’ publication by stakeholders, as described in section five of this case study, has *contributed* to the following outcomes:

<table>
<thead>
<tr>
<th>Outcome</th>
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<tr>
<td>Improved processes for the collection of CVI data at hospitals and registration data at local authorities, which is likely to have enabled:</td>
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<td>- more blind and partially sighted people to engage with social care providers</td>
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<td>- epidemiological analysis on causes of</td>
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<td>Certifications Office comparing CVI and registration data and subsequently investigating significant variances</td>
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Version: 1.1
Date: 11/11/2014
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<tr>
<th>Outcome</th>
<th>Activity contributing to outcome</th>
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<td>visual impairment being conducted against a more complete population</td>
<td>Guide Dogs planning future service needs based on relevant information sources, including the ‘Registered Blind and Partially Sighted People’ publication</td>
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<td>Improved planning and delivery of services, which has resulted in the right type of visual impairment services being made available, and at the point of need. This has led to:</td>
<td>Guide Dogs planning future service needs based on relevant information sources, including the ‘Registered Blind and Partially Sighted People’ publication</td>
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<td>• more blind and partially sighted people living independently</td>
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<tr>
<td>• more blind and partially sighted people partaking in community activities and events</td>
<td>Guide Dogs planning future service needs based on relevant information sources, including the ‘Registered Blind and Partially Sighted People’ publication</td>
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<td>• fewer blind and partially sighted people living in isolation</td>
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<td>Local plans better reflect the health profile of local populations, in order that services are better tailored for people who are blind and partially sighted</td>
<td>The inclusion of RNIB’s SLDT and ‘Registered Blind and Partially Sighted People’ publication data in local JSNAs and local vision strategies</td>
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<td>Increase in the provision of visual impairment services</td>
<td>Guide Dogs engaging with local bodies to incorporate service needs of people affected by sight loss into local plans</td>
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<td>The inclusion of RNIB’s SLDT and ‘Registered Blind and Partially Sighted People’ publication data in local JSNAs and local vision strategies</td>
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<td>Guide Dogs engaging with local bodies to incorporate service needs of people affected by sight loss into local plans</td>
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<tr>
<td>Increase in the provision of visual impairment services</td>
<td>Development and implementation of local vision strategies</td>
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<td>Development of JSNAs</td>
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### 7 Benefit in the provision and delivery of visual impairment services

The use of the ‘Registered Blind and Partially Sighted People’ publication by stakeholders, as described in section five, has contributed to the following benefit.

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<tr>
<th>1</th>
<th>Benefit</th>
<th>Activity contributing to benefit</th>
<th>Key beneficiaries</th>
<th>Improvement</th>
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</table>
|   | An increase in the number of ECLOs at eye clinics, which enables more blind and partially sighted people receiving post-diagnosis support and guidance | RNIB and partners presenting funding proposals for ECLOs to relevant bodies | People registered blind and partially sighted, NHS acute trusts | Increase in the provision of ECLOs between 2009 and 2014
   |   |   |   |   |
   |   |   |   |   | • In 2009 there were:
   |   |   |   |   |   o 27 trained ECLOs funded by the RNIB group of charities
   |   |   |   |   |   o 69 sight loss advisers including trained ECLOs, hospital information officers and eye clinic volunteers were provided by local sight loss charities (it is not possible to determine
how this 69 splits into each of the stated roles).

- As at 31 March 2014 there were:
  - 48 trained ECLOs funded by the RNIB group of charities
  - 20 trained ECLOs funded by NHS
  - 3 trained ECLOs funded by local authorities
  - 29 trained ECLOs employed by local sight loss charities.

- As at 31 March 2014, support was provided in a total of 217 eye clinics by sight loss advisers (qualified ECLOs, eye clinic volunteers and other similar roles) employed by other organisations.

8 Contributions

This case study has had contributions from, and been reviewed and approved by the following individuals:

- Dr Philippa Simkiss, Head of evidence and service impact, RNIB
- Catey Bunce, Principal statistician, Moorfields Eye Hospital NHS Foundation Trust
- Carl Freeman, Policy manager, Guide Dogs
- Phil Ambler, Policy director, Thomas Pocklington Trust

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6 The Royal College of Ophthalmologists. *CVI Data* [Online] Available at: [http://www.rcophth.ac.uk/page.asp?section=647&sectionTitle=CVI+Data](http://www.rcophth.ac.uk/page.asp?section=647&sectionTitle=CVI+Data) [Accessed 21 October 2014]


