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Health and social care information for visually-impaired people

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Abstract

Purpose - The purpose of this study was to examine the health and social care information needs of people with a visual impairment; to identify the health and social care information sources used by visually-impaired people seeking information; to identify differences in the information needs of people with different visual impairments; to examine ways in which developments in information provision may help to meet the needs of visually impaired people.

Design/methodology/approach - 28 semi-structured interviews (face-to-face or telephone) were conducted with 31 visually impaired people living in or near Sheffield, UK. The participants included two groups: people with an age-related visual impairment and people with a visual impairment since birth or early childhood. Framework analysis was used to analyse the findings.

Findings - Four major themes were identified: health and social care information needs; sources of health and social care information; possible improvements; and "intervening variables".

Practical implications - In this study only a small proportion of the health and social care information needs of visually impaired people were currently being met. There was minimal co-ordination of information between the different information providers. Visually impaired people were dependent on acquiring and seeking out additional information from a wide variety of sources.

Originality/value - This paper provides new insights into the health and social care information needs of visually-impaired people and their sources of information, and starts to fill gaps identified in an earlier systematic review. The paper reinforces the view that visually impaired people are a heterogeneous group, with different needs according to their visual impairments.

Keywords Visually-impaired persons, Information needs, Health service needs and demand

Paper type Research paper

Introduction

An estimated 161 million people worldwide have some degree of visual impairment (Resnikoff *et al.*, 2004), including one million people in the United Kingdom, which accounts for 1.8 per cent of the population (European Blind Union, 2002). There are various formal definitions of visual impairment (e.g., Bruce and Baker, 2001; European Blind Union, 2002) covering a broad spectrum of people, ranging from people who are completely blind to those who are partially-sighted. There are many different types and causes of visual impairment, including glaucoma, cataracts and detached retina. The age at which people first experience visual impairment ranges from birth (e.g., coloboma) to advanced old age(e.g., age-related macular degeneration) (Ghafour, 1983; RNIB, 2009). Visual impairment is also frequently experienced along with other disabilities or illnesses, some of which might be permanent, such as arthritis, heart conditions, mobility problems, diabetes and hearing impairment (Bruce *et al.*, 1991). People with a visual impairment are, therefore, often regular users of health and social care services, due either to the visual impairment itself, or due to these co-morbidities.

Literature review

Information has an important role in helping to support and improve people's health and social care, particularly in the information society of the 21st Century (Darzi, 2008). However, information is not always accessible to or appropriately "packaged" for visually impaired people. A systematic review showed that information is not always provided in an appropriate format, at the right time, or in sufficient detail (Beverley *et al.*, 2004). Although guidance exists on the information health and social care providers should provide to visually impaired people (e.g., Association of Directors of Social Services, 2002), this has not been widely adopted in practice or based on research evidence. Very little literature has been published specifically on the health and social care "information behaviour" (Case, 2002), i.e., information needs, information sources and information seeking behaviour, of people with a visual impairment. The most substantial piece of work in this field was a systematic and critical review of the health information needs of visually impaired people (Beverley *et al.*, 2004). This review identified over 1,000 references, but only 16 studies met the inclusion criteria. The authors expressed concern about the quality of the reporting of these studies. The majority of studies were concerned with information for healthy living, such as health promotion, including sexual health (e.g., Welbourne *et al.,* 1983; Hayes, 1999; Duh, 2000), parenting (e.g., Conley-Jung and Olkin, 2001), dental health (e.g., Schnuth, 1977), breast self-examination (Albright and Toy, 1993), and general health (Hall et al., 2000, Ivanoff et al., 1996). The focus of the remaining studies was on information about visual impairment or coping with visual impairment (Moore et al., 1992; Ivanoff et al., 1996; Donnelly, 1997a, b; Ahmed *et al.*, 2001) and about accessing health services, such as appointment letters, test results, medication labels, and general medical information (e.g., Grills and MacDonald, 1997; RNIB, 1998; Bruce and Baker, 2001). The majority of studies concentrated on the format of information that is provided rather than on the actual information needs of visually-impaired people.

Beverley *et al.'s.* (2004) review had a narrow focus, only explicitly addressing health information. A further 13, more generic, studies (Arsnow *et al.*, 1985; Biegel *et al.*, 1989; Jinks *et al.*, 2001; Parette *et al.*, 1990; Javed, 1993; Landes and Popay, 1993; Williams, 1993; Marsland *et al.*, 1994; Petterson, 1994; Ivanoff *et al.*, 1996; RNIB, 1998; RNIB, 2001; RNIB Cymru, 2001) were identified in an earlier review (Beverley *et al.,* 2002). Of particular interest were the studies by Landes and Popay (1993) and the RNIB (2001a) which investigated the health and social care needs of people with vision problems. Several additional studies have been published since the Beverley *et al.* (2004) review. These include follow-ups to the Ivanoff *et al.* (1996) study exploring a health education programme for elderly people with a visual impairment (Ivanoff *et al.*, 2002; Eklund *et al.*, 2004), as well as several studies (Allwinkle, 2002; Fox *et al.*, 2002; Williams, 2002; Rubinstein *et al.*, 2003; Uslan *et al.*, 2003) which have specifically considered the additional barriers faced by visually-impaired diabetic people. In addition, the Guide Dogs for the Blind Association published a study examining the experiences of visually-impaired users of the NHS (Nzegwu, 2004). On the whole, the findings of these studies echoed the findings of the Beverley *et al.* (2004) review.

It is clear that the studies conducted to date have failed to address other aspects of information provision, such as the content, design, timing and support mechanisms (Beverley *et al.*, 2004). Patients need appropriate information, for example, relating to their condition and the likely outcomes with and without treatment, at the right time and in a format which is accessible. This is particularly important for people with a visual impairment, because the nature of their condition can act not only as a barrier to information, but to being aware of what information is available. Work by Papadopoulos and Scanlon (2002) showed that visually impaired people wanted information to be provided in "plain English" and other languages at the time of diagnosis, as well as in alternative formats, for example, large print, audio tape and Braille. The present study seeks to contribute to the emergence of an evidence base (Coulter, 1998), upon which the development of information for people with a visual impairment could be based.

An important consideration is that visually-impaired people should not be regarded as a single homogenous group (Beverley *et al*., 2004). It is evident that the approach to health and social care information provision has been largely uncoordinated and that visually impaired people have not been involved in the design and conduct of research in this field.

Developing an understanding of the information needs and information behaviours of visually impaired people could help to provide information that is targeted at particular sub-groups and individuals, and in turn might lead to more effective interventions. This approach has been successful with other groups; for example, Jones *et al.* (2006) demonstrated that providing personalised information to cancer patients was more effective than providing generalised information. This intervention was based on prior knowledge of information behaviours and coping styles and on a previous study investigating patients' preferences for information (Jones, 1999). Although Kiesler and Auerbach's review (2006) of studies of patient preferences for information decision-making and interpersonal behaviour reported some variation in the positive effects of matching information provision to individual needs and behaviours, the authors concluded that "the more the information received by patients matched their preferences, the better their adjustment to treatment" (p. 336).

Aims and objectives

The overall aim of the study described here, therefore, was to build on the existing research and increase our knowledge and understanding of the information needs of people with a visual impairment, with particular reference to health and social care information. More specifically, the objectives for the research were:

- To identify the health and social care information needs of people with a visual impairment.
- To identify the information sources used by people seeking health and social care information.
- To examine any differences in the information needs of people with visual impairments who have had their impairment since birth compared with those who acquire their visual impairment in later life.
- To examine how developments in information provision (e.g., NHS Direct and the Internet) help to meet the needs of visually impaired people.

The study was part of a larger scale study (Beverley, 2009) which also examined the information behaviour of visually impaired people within the context of existing information models (e.g., Wilson, 1999; Moore, 2002) described elsewhere (Beverley *et al.*, 2007).

Methods

The research was conducted within a constructivist paradigm. Constructivism views the world as a constantly changing place where individuals have varying perceptions of a given situation (Dootson, 1995). A qualitative approach was adopted, comprising individual semi-structured interviews with two groups of visually impaired people; people with an **a**ge-related visual impairment (Group **A**) and people with a visual impairment since **b**irth or early childhood (Group **B**). This approach was devised in response to the findings of the literature reviews in Beverley et al. (2004) and Beverley (2009) (e.g., Duckett and Pratt, 2001), a consultation exercise with visually impaired people, and suggestions made by five visually impaired advisors to this study. In order to obtain as wide a range of views as possible, participants were recruited on the basis of having a visual impairment, irrespective of the type of impairment, and the interviews were conducted and the data were analysed to identify any differences between those who had had a visual impairment since birth/early childhood and those who had acquired a visual impairment in later life.

Several recruitment routes was exploited, including placing an advert in the Sheffield Talking News and a local newsletter for visually impaired people, as well as via local visual impairment support groups and referrals from the local society for the blind.

Participants were given the choice of the type of interview (face-to-face or telephone) and venue for the interview. An information sheet was sent to all participants in their preferred format (i.e., large print, audio tape or e-mail). Verbal consent was obtained from participants at the start of the interview.

A topic guide was used to structure the interviews and revised in response to feedback during the pilot study. The interviews covered the information participants had received, sought or acquired in connection with their visual impairment and/or other aspects of their health and social care. Interviewees were also asked to suggest ways in which the existing provision of health and social care information could be improved for people with a visual impairment.

The tape recorded interview data were transcribed verbatim. The transcripts were analysed manually using framework analysis (Ritchie and Spencer, 1994). Demographic data collected for each participant were analysed using *Statistical Package for the Social Sciences* (*SPSS*).

Framework analysis is a relatively new approach to qualitative data analysis which has gained popularity particularly in health-related research (Ritchie and Spencer, 1994; Lacey and Luff, 2001). Framework analysis follows a well-defined procedure (Miles and Hubermann, 1994; Ritchie and Spencer, 1994) and provides a systematic, transparent, accessible and robust approach to qualitative data analysis (Lacey and Luff, 2001). Although the general approach to framework analysis is inductive, being heavily based in the original accounts of the people studied (i.e., "grounded"), it starts deductively from the aims and objectives for the study (Pope and Mays, 1999). However, the approach is flexible, allowing the inclusion of emergent concepts (Lacey and Luff, 2001). An initial thematic framework was developed based on the interview topic guide and familiarisation with the data. A single index was developed across the two interview groups, with differences between the groups highlighted. The final framework was shared and discussed with the participants and the visually impaired advisors to this study.

Results and discussion

Participant characteristics

Twenty-eight interviews were conducted in total. This equated to 31 people, because three visually impaired couples were interviewed together at their request. Sixteen of the interviews (17 people) were conducted with people from Group **A** (those with an **a**ge-related visual impairment), and 12 interviews (14 people) were conducted with people from Group **B** (those with a visual impairment since **b**irth or early childhood). Twenty-three interviewees chose to have a face-to-face interview in their own home; one interviewee opted for a face-to-face interview at the University, while seven expressed a preference for a telephone interview. All of the people opting for a telephone interview came from Group B. The mean interview duration was 45.54 minutes (range: 18-131 minutes); the duration being longer for Group A participants (50.56 minutes, compared to 38.83 minutes).

Table I presents the major demographic characteristics of the participants. The mean interviewee age was 62.42 years (range: 19-91 years), with Group A participants having a greater mean age (80.24 years, compared to 40.79 years). In total, 15 men and 16 women were interviewed. However, this was not equally distributed across the two interview groups. The majority of participants were white-British. Approximately one third of participants lived alone; this figure being higher amongst people from Group A.

Take in Table I. The major demographic characteristics of the interview participants

The characteristics of the participants in terms of their visual impairment are presented in Table II. The type of visual impairment experienced by participants varied considerably between the two groups. The majority of Group A interviewees had a diagnosis of AMD, with or without cataracts. Most interviewees had had a visual impairment for more than 12 months and were registered blind or partially sighted. Over three quarters of participants experienced other health conditions (e.g., breathing difficulties, arthritis, heart problems, hearing impairment); this figure being higher amongst Group A participants.

Take in Table II. The characteristics of the interview participants in terms of their visual impairment

Interview themes

The framework developed from the analyses comprised four major themes and various sub-themes (shown in Figure 1). This section describes these themes, in particular focussing on the health and social care information needs (Theme A) and the sources of health and social care information (Theme B). Themes C and D are described in detail elsewhere (Beverley, 2009; Beverley *et al.,* 2007). Illustrative quotes are provided: these are coded using a letter (A or B, depending on the type of visual impairment), a number (A1-A17 and B1-B14 according to the participant), and the line numbers from the corresponding transcript.

Take in Figure 1. The major interview themes and sub-themes

Theme A - health and social care information needs

Generally, the health and social care information needs of people participating in this study mirrored the eight "clusters" identified by Moore (2000). Visually impaired people, therefore, had information needs relating to the following aspects of their health and social care:

- Their eye condition, in particular information about the diagnosis, prognosis, treatment options, and causes.
- Health and social care services and facilities.
- Aids, adaptations and equipment.
- General health care, including techniques for administering medications and reading medical information.
- Benefits and money.
- Mobility, including using public transport, shopping, eating out, etc.
- Housing and accommodation, including performing household chores.
- Employment, education and training.

Participants' responses could be classified into the information they had received (i.e., been given), acquired (i.e., obtained passively from family, friends, support groups, the media, etc.), or sought (i.e., actively searched for). In addition, it was clear that, whereas some participants could be thought of as "expert patients" (i.e., they had obtained specialist knowledge about their visual impairment), others clearly had a wide range of "outstanding information needs". This qualitative study, therefore, builds on other quantitative studies in the field (e.g., Moore *et al.*, 1992; Ivanoff *et al.*, 1996; Grills and MacDonald, 1997; Bruce and Baker, 2001; Papadopoulos and Scanlon, 2002) by identifying how and where visually impaired people obtain this information, as well as highlighting their unmet information needs.

In terms of the "information received", the quantity of information ranged from:

> Very little … apart from putting a label on what I've supposedly got … nothing! (B6)
>
> to:
>
> Well, I think I've had all the information that's available ... (A7)

For people in this research study, health and social care providers only met some of visually impaired peoples' information needs. It was clear that many participants had either to seek additional information themselves, or they "acquired" information from family, friends, local support groups and the mass media.

Participants generally received information about their eye condition, such as diagnosis information, prognosis information and information about treatment options; the health and social care services that were available to them (e.g., magnifiers and lamps via the low vision clinic, mobility training via Social Services); and the aids, adaptations and equipment available via the local society for the blind (e.g., white canes, talking books, talking watches, liquid level indicators, coin holders). The majority of this information was provided verbally, although over recent years information was increasingly being provided in written format as well.

Participants also "acquired" additional information from a variety of different sources (e.g., family, friends, support groups, television, radio, newspapers, magazines), as illustrated by the following quotes:

> It's people I know who've got problems with their eyes that have told me a lot …. (A13)

> Sometimes … one hears by word of mouth, of course … Somebody else will say, 'Oh, have you tried this?', or "Did you know you could get that?" (A3)

In addition to acquiring additional information relating to the categories previously described (i.e., the eye condition; health and social care services; and aids, adaptations and equipment), participants also acquired information about general health care, such as administering medications (e.g., eye drops and tablets); benefits and money; and mobility. For example, participants used a number of innovative approaches to help them to administer medications, both for their visual impairment and for other health conditions. These "information aids" included enlisting the help of friends and family to read medication labels, using touch to recognise tablet packages, and using a colour coding system to identify different tablets.

In terms of "information sought", participants from Group B tended to seek more information than people from Group A. Several participants indicated that they had not attempted to seek any information themselves about their visual impairment, believing that either they had all the information they required; they did not know what further information they needed; or they knew where to go for more information but the need had never arisen.

On the other hand, it was clear that participants had to be assertive and ask for information explicitly:

> Well, the thing is … you do not get information either from your GP or the hospital unless you ask … and sometimes they think it's an impertinence to do this … (A2, lines 181-183)

The findings also suggest that most of the information that visually impaired people require is actually already available within the public domain. However, information providers need to be more effective about disseminating this information; for example, in alternative formats (RNIB, 1998; Hall *et al.*, 2000; Beverley *et al.*, 2004). People with visual impairments also need to be more involved in developing information services to ensure that the information provided is appropriate and timely (Donnelly, 1997a, b; Masey, 1997). The implementation of the *Disability Discrimination Act 1995* (The Stationery Office, 1995) should hopefully have helped in this respect.

Participants clearly had various "outstanding information needs"; these often emerged from descriptions of the difficulties participants experienced in aspects of their daily life. In general, the outstanding information needs reflected the information that participants sought. For example, the following quotes illustrate how participants were curious about the cause(s) of their visual impairment:

> This macular thing, off the record, I think it must be hereditary thing, because I had two uncles and an aunt who went blind on m' Dad's side of the family … (A2)

Participants' major unmet information needs related to the causes of their visual impairment, reading correspondence, the financial benefits they were entitled to, and general mobility issues, such as using public transport. Although the focus of the research was on the health and social care information needs of people with a visual impairment, participants tended to focus on their social care information needs. This finding contrasts with the results of the systematic review by Beverley *et al.* (2004), which identified "information for healthy living" as a major type of information required by visually impaired people.

Several participants also highlighted the problems they encountered in reading medical information (appointment letters, prescriptions, medicine labels, hospital notices and signs, etc.); for example:

> … like for our medical appointments … things of that nature … err … they don't call and tell us … they send us print notes through the door … (B8)

In addition, it was evident that participants had information needs relating to two additional categories: housing and accommodation (including performing household chores), and employment, education and training.

Theme B - sources of health and social care information

Participants obtained their health and social care information from six major sources: health care professionals (i.e., opticians, ophthalmologists, orthoptic nurses, and general practitioners); social care professionals (i.e., social workers and care workers); societies, organisations and support groups (i.e., the local voluntary society for the blind, local support groups, national visual impairment organizations); friends and family; schools and the mass media (i.e., television, radio, (talking) newspapers and magazines, etc.). Health care professionals were a, if not *the*, major source of information for participants.

Health care professionals, in particular ophthalmologists, were the major providers of information about different eye conditions, whereas the local society for the blind and Social Services were the major providers of social care information. Interestingly, Social Services only had a limited role to play in meeting participants' information needs. This may be because many of the services provided by Social Services are outsourced to the local society for the blind in Sheffield. The fact that many participants found out about these organizations by word of mouth, rather than through formal channels, must, however, be addressed. It was also clear that friends and families and the mass media were a valuable source of information.

Most Group A participants initially went to see an optician. Some participants went because they experienced sight problems, whereas others simply went for a routine check-up. At this stage, participants were most interested in knowing about the diagnosis and prognosis of their eye condition. Participants were subsequently referred to the ophthalmology department at the local acute hospital. However, it emerged that not all participants were clear about why they were being sent to the ophthalmology department; for example:

> … he just said, ‘Go straight away’. And … err … I’d no idea really what I was going for. (A1)

Staff at the ophthalmology department provided the majority of participants with information about their eye condition and the services available to them. Several participants who had been diagnosed over the last 18 months specifically referred to a booklet which they had received:

> Yes, we got that … big book … yellow book, didn’t we? … The Specialist gave been a big book on what I could do, what I couldn’t do, and what I could get, you know … (A4)

However, some participants expressed concern about the way in which their visual impairment was diagnosed and communicated to them by the ophthalmology department:

> So they said, “Well, it all depends. You might go to bed one night and wake up blind in the morning … or you might go for 10 years and you’ll not worry very much”. And then he said … to the nurse, “Next”. So it was a bit of a shock that. (A3)

As noted previously, several participants commented on having to ask for further information explicitly:

> Erm … the people at the hospital often don’t like to say things … and you have to ask them very specific questions to get an answer. (B1)

Other participants could not remember what information they had actually received. The timing of this information was questioned by some people. For example, for most participants the greater part of the information was provided by an ophthalmologist immediately after their visual impairment had been diagnosed, which shocked most participants.

Participants expressed several concerns about the information they received and/or sought from health care professionals. For example, opticians’ and GPs’ knowledge of different eye conditions was highly variable and this contributed to participants’ anxiety at what was already a traumatic time. Several participants could not remember what, if any, information they had actually received from their ophthalmologist. Although this may be explained by the long period that had elapsed from the time of diagnosis for some participants, it may also indicate the method of communication (predominantly verbal) was not always effective in the longer term. In Sheffield, attempts have already been made to address this; for example, by providing an information booklet at the time of diagnosis. It was also clear that participants felt that their consultations with the ophthalmologists were rushed and did not allow sufficient time for issues to be explored in depth. Instead participants had to come back with a series of prepared questions. This is of particular concern, because it suggests that only a few persistent people were actually provided with the information that they needed in order to make informed choices about their visual impairment. In order to address this, the authors believe there is potential to explore further the role of hospital "drop-in" advice sessions.

It is clear from these findings that there needs to be a more co-ordinated and targeted approach to information provision on health and social care issues for visually impaired people (Ahmed *et al.*, 2001; RNIB, 2001). Interestingly, this was identified as an issue by participants themselves. At the moment, there is a wealth of information, but it appears that this is not always readily available and/or accessible to visually impaired people. Instead of addressing individuals' outstanding information needs, there is considerable duplication of information across different organisations (e.g., between Social Services and the local society for the blind) and, hence, confusion amongst visually-impaired people about the most appropriate source of information. There is also insufficient sharing of information between, and even within, organisations. Although there are obviously confidentiality issues to consider, the drive towards more integrated health and social care services should help in this respect.

Another major source of information was the staff (e.g., orthoptists) at the low vision clinic. These staff provided information about low vision aids (such as magnifiers), as well as further details about specific eye conditions and various services available to visually impaired people. However, it was evident that referral to the low vision clinic was not automatic and some participants were not even aware of the service. Finally, a few participants specifically mentioned seeking information from their GP. However, one participant expressed concern about their GP's lack of knowledge about eye conditions:

> … he didn't know what on earth I was talking about … so … I do know that some GPs are not at all clued up on eye conditions. (B12)

Participants also received information from a variety of social care professionals, including social and other care workers, as well as from individually-hired home helps. Social workers were responsible for providing information and support on a wide range of social care issues, including mobility training, financial benefits, form filling, home adaptations (such as walk-in showers, grab rails, liquid level indicators, bump-ons, etc.) and details of local visual impairment support groups. However, there was some confusion about the initial method of contact with Social Services; for example, many participants had to contact Social Services themselves.

Various societies, organizations and local support groups catered for a variety of participants' outstanding information needs. The local society for the blind, for example, directed users to appropriate health and social care services, offered advice about financial benefits, provided practical assistance in filling forms out, organized social events, arranged talking books, and advised on the availability and use of aids, adaptations and equipment. Some participants had heard about the society via friends and family, rather than through formal channels.

Friends and family were a valuable source of "acquired" information for many participants, and also helped participants to read written information. For Group B participants, schools were responsible for raising awareness of health and social care services available to visually impaired people. Participants also acquired information about eye conditions, treatment options and services from a variety of local media sources (e.g., Sheffield Talking News), as well as national media sources (e.g., New Beacon, the Royal National Institute for the Blind (RNIB) magazine, and BBC Radio 4's "In Touch" programme). Several participants, however, recognised the potential bias of information reported by the media.

The participants' preferred information source for health and social care information varied considerably. However, all participants stated that they would prefer to speak to a person, be that a health professional, social care professional, or someone at a local or national society, organisation or support group. In general, participants directed questions relating to their eye condition to their ophthalmologist, and questions relating to social care issues to the local society for the blind or Social Services.

One of the criticisms of previous research in this field has been that there was a tendency to treat visually impaired people as a homogeneous group (Beverley *et al*., 2004). This research study attempted to address this by examining the similarities and differences between two groups of visually impaired people. Interestingly the overarching themes were very similar between the two groups, as illustrated by the decision to develop a single index in the framework analysis. However, there were several important differences which are worthy of discussion.

First, Group A participants tended to rely more on the information that they received and were less likely to seek information independently themselves. For Group B participants, schools were a useful source of information, particularly about the services and facilities available to them and their families. On the whole, Group B participants were more enthusiastic about using the Internet to search for health and social care information. This may be due to age or cohort differences, i.e., because a larger proportion of this group were aged under 40 years and had learnt to use a computer either at school, college or their place of work. Participants from Group B raised the issue of alternative formats considerably more often than Group A participants. Finally, it is interesting to note that all participants opting for a telephone interview were from Group B which suggests that these people were more comfortable communicating by telephone. Many people from Group A also lived alone and valued face-to-face contact.

This research has demonstrated that the type of visual impairment is only one factor which needs to be considered when undertaking research with visually impaired people. There were, for example, considerable differences (referred to as "intervening variables" in this study) within each of the two groups, particularly within Group B. These variables are similar to the barriers and facilitators identified in the Beverley *et al.* (2004) review. For example, people with other health conditions and disabilities are likely to have a more acute need for accessible information relating to other aspects of their health and social care. In addition, social identity factors, such as age, gender, and ethnic origin, may influence visually impaired people's information needs.

The interviews also explored participants' opinions about newer sources of information, in particular NHS Direct and the Internet. Many participants had never heard of NHS Direct and even fewer people had actually used the service. However, participants seemed very interested in the concept of NHS Direct after the interviewer explained the service in more detail, as illustrated by the following quote:

> Ooh, can you put it me in my book then? (A6)

It also emerged that several participants had heard of NHS Direct but had either forgotten about it or did not think that it was relevant to them. Most participants were comfortable with the idea of receiving health information and advice over the telephone; however, some people expressed a preference to speak to someone face-to-face.

Opinions about the Internet as a source of health and social care information varied considerably. The following quotes were typical of many participants:

> That's a swear word to me! It really frustrates me. (B4)

> Don't mention that word to me! I hate all mention of Internet … web site … and all this dreadful stuff that's going on with the abuse of it. (A12)

Participants gave a variety of reasons for their lack of use of the Internet. These included not being able to use a computer; difficulties in reading information on a computer screen; problems setting up their computer to access the Internet; the expense of buying a computer and connecting it to the Internet; a lack of space to keep a computer; as well as a lack of interest in using a computer. However, other participants stated that the Internet was a valuable source of information on a wide range of issues and that not being able to access the Internet disadvantaged them. Participants generally used generic search engines, such as Google, to search for health and social care information. Some participants (all from Group B) expressed concern about the quality of the information provided on the Internet.

Newer sources of information, such as those discussed here, for example, NHS Direct and the Internet, have the potential to address some of the outstanding information needs of visually impaired people. It is important, however, that people with a visual impairment are actively involved in shaping these services and sources in the future. This study suggests that NHS Direct needs to be promoted more actively to visually impaired people. It is also important to ensure that the barriers to Internet use are addressed and that the public are made more aware of specialist online health and social care resources, such as Intute, formerly known as OMNI (Organizing Medical Networked Information).

Theme C - possible improvements in the provision of health and social care information

The majority of participants identified at least one area requiring improvement regarding the provision of health and social care information. From participants' comments it was clear that there needed to be a more co-ordinated and targeted approach to information provision across the wide range of information sources. Suggestions included increased sharing of personal information between health and social care services to improve efficiency, providing an "information pack" at the time of diagnosis, providing information at local GP practices and libraries, as well as setting up a national telephone helpline for visually impaired people. Many participants also wanted information to be provided in a person's preferred format automatically, and for a variety of media (e.g., verbal and written) to be used depending on the nature of the information being conveyed. Some participants also went on to suggest improvements to a variety of different services, ranging from public transport to notices in shops and restaurants.

Theme D – "Intervening variables"

The interviews identified a number of factors, referred to here as "intervening variables", which could potentially affect participants' information needs and their being able to access the information they required. These related to the presence of other health conditions or disabilities; participants' understanding of the word "information"; their interactions with information providers; their degree of independence; the support they received from friends and family; their acceptance of their own visual impairment, as well as their awareness of other visual impairments; their registration status; and their willingness and ability to pay for aids, adaptations and equipment. For example, some participants defined information solely in terms of the information that they received, whereas other participants emphasized the two-way flow of information. It also emerged that participants' interactions (positive and negative) with the different information providers and their progression through the various health and social care services affected their information needs. Some participants were clearly very independent and did not want to have to rely on other people in order to address their information needs. In contrast, other participants acknowledged that their visual impairment had caused them to lose some of *their* independence. The participants' acceptance of having a visual impairment varied considerably; for example, the majority of Group B participants had, over the years, come to terms with being visually impaired and had developed coping strategies. These "intervening variables" are discussed in more detail elsewhere (Beverley, 2009; Beverley *et al.*, 2007).

Limitations

This study was based on a relatively small sample size. Data saturation was, however, reached after 24 interviews and qualitative research does not aim to be generalisable (Lincoln and Guba, 1985). For practical reasons, a convenience self-selecting sampling frame was used. It is, therefore, possible, that the people who volunteered to be interviewed were more confident and active in seeking out information than non-responders. The majority of participants was white-British, had had a visual impairment for more than twelve months and was registered and was, therefore, already in contact with relevant services. It is not clear if the findings could be applied to newly diagnosed people and/or people from other ethnic groups, many of whom have an additional language barrier. There may also have been substantial differences between the two groups of people interviewed, other than their visual impairment which may have accounted for some of the differences in information needs. Finally, data analysis was carried out by only one researcher (Mays and Pope (1995) recommended that the reliability of qualitative data analysis be enhanced by different analysts independently assessing the transcripts and comparing the results. However, due to financial constraints, this was not possible), although the framework was discussed with the other researchers during the analysis.

Conclusions

To conclude, this interview study has clearly identified the health and social care information needs of a group of visually impaired people within an urban area. Only a small proportion of these needs were currently being met by information providers, mainly health care professionals at the hospital ophthalmology department. Visually impaired people were dependent on acquiring and seeking additional information independently from a wide variety of sources. A local society for the blind was responsible for meeting numerous information needs. Information providers did not provide information consistently in the person's preferred format. There was also much duplication of effort in terms of the provision of information. This study has also reinforced the authors' belief that visually impaired people are a heterogeneous group, with different visual impairments, as well as personal characteristics and preferences. Although current developments in information provision, such as NHS Direct and the Internet, have the potential to improve access to health and social care information to visually impaired people, they are still in their infancy and various barriers must be overcome before they can be considered a viable addition to existing information sources. Although, this study has started to fill the knowledge gaps identified in the original systematic review (Beverley *et al*., 2004), further quantitative research could test the generalisability of these findings to the wider population of people with a visual impairment.

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References

Ahmed, F. Cheeseman C. and Rodin M. (2001), *Why can't you see me? A study into the needs of people with visual impairment from ethnic communities living in a London Borough*, SeeAbility, London.

Albright , P. and Toy K.W. (1993), "Breast self-examination for visually impaired women", *Public Health Reports*, Vol. 108, No. 2, pp.147-150.

Allwinkle, J. (2002), "Blood glucose monitoring for visually impaired people with diabetes", *Journal of Diabetes Nursing,* Vol. 6 No. 5, pp.157-159.

Arsnow, G.F.D.J., Mould, L., Sauerburger, D. and Peaco F. (1985), "Blind parents rearing sighted children", *Journal of Visual Impairment and Blindness* Vol. 79, No. 5, pp. 193-198.

Association of Directors of Social Services (2002), *Progress in Sight – National Standards of Social Care for Visually Impaired Adults*, Disabilities Committee of the Association of Directors of Social Services, London.

Beverley, C., Bath, P.A. and Booth, A. (2004), "Health information needs of visually impaired people: a systematic review of the literature", *Health and Social Care in the Community* Vol. 12 No. 1, pp. 1-24.

Beverley, C., Bath, P.A. and Booth, A. (2002), *The Health Information Needs of Visually Impaired Groups: A Systematic Review of the Literature,* Public Health Strategy Division, Welsh Assembly Government, Cardiff. Unpublished report.

Beverley, C., Bath, P.A. and Barber, R. (2007), "Can two established information models explain the information behaviour of visually impaired people seeking health and social care information?", *Journal of Documentation,* Vol. 63 No. 1, pp. 9-32.

Beverley, C. (2009), *The Health and Social Care Information Behaviour of People with a Visual Impairment,* PhD thesis, Information School, University of Sheffield, Sheffield.

Biegel, D.E., Petchers M.K., Snyder A. and Beisgen B. (1989), "Unmet needs and barriers to service delivery for the blind and visually impaired elderly", *Gerontologist,* Vol. 29, No. 1, , pp. 86-91.

Bruce, I. and Baker, M. (2001) *Access to Written Information: The Views of 1,000 People with Sight Problems*, RNIB, London.

Bruce, I., McKennell, A. and Walker, E. (1991), *Blind and Partially Sighted Adults in Britain: the RNIB Survey,* RNIB, London.

Case, D.O. (2002), *Looking for Information: A Survey of Research on Information Seeking, Needs, and Behavior*, Academic Press, London.

Conley-Jung, C. and Olkin, R. (2001), "Mothers with visual impairments who are raising young children", *Journal of Visual Impairment and Blindness,* Vol. 95 No. 1, pp. 14-29.

Coulter, A. (1998) "Evidence based patient information", *British Medical Journal* 317(7153) 225–6.

Darzi, A. (2008), High quality care for all: NHS Next Stage Review final report. Department of Health, London.

Donnelly, D. (1987a), "Focus on disability: information gap... being registered blind", *Nursing Times,* Vol. 83, No. 25, pp.55-56.

Donnelly, D. (1987b), "Focus on disability: registered hopeless?" *Nursing Times,* Vol. 83, No. 24, pp. 49-50.

Dootson, S. (1995), "An in-depth study of triangulation", *Journal of Advanced Nursing,* Vol. 22 No. 1, pp. 183-187.

Duckett, P.S. and Pratt, R. (2001) "The researched opinions in research: visually impaired people and visual impairment research", *Disability and Society,* Vol. 16 No. 6, pp. 815-835.

Duh, J. (2000), "Sexual knowledge of Taiwanese adolescents with and without visual impairments", *Journal of Visual Impairment and Blindness,* Vol. 94 No. 6, pp. 385-395.

Eklund, K., Sonn, U. and Dahlin-Ivaboff, S. (2004) “Long-term evaluation of a health education programme for elderly persons with visual impairment: a randomized study”, *Disability and Rehabilitation* ,Vol. 26 No. 7, pp. 401-409.

European Blind Union (2002), *Statistics: United Kingdom*, available at: http://www.euroblind.org/fichersGB/statUK.htm (accessed 4 January 2002).

Fox, C., McKinnon. C., Wall. A. and Lawton, S.A. (2002), “Ability to handle, and patient preference for, insulin delivery devices in visually impaired patients with type 2 diabetes”, *Practical Diabetes International,* Vol. 19 No. 4, pp. 104-107.

Ghafour, M., Allan, D., and Foulds, W.S. (1983), “Common causes of blindness and visual handicap in the West of Scotland”, *British Journal of Opthalmology*, Vol. 67, No. 4, pp. 209-213.

Grills, A. and MacDonald, A. (1997), “An assessment of the pharmaceutical needs of the blind and partially sighted in Dumfries and Galloway”, *Pharmaceutical Journal*, Vol. 259, No. 6959, pp. 381-384.

Hall, D., Boswell, C. and Mills, D. (2000), *Health Promotion with Visually Impaired People*, Opinion Research Services Ltd on behalf of Wales Council for the Blind, Wales.

Hayes, B. (1999), “Availability of appropriately packaged information on sexual health for people who are legally blind”, *Australian Journal of Rural Health*, Vol. 7, No. 3, pp. 155-159.

Ivanoff, S.D., Sonn, U. and Svensson, E. (2002), “A health education program for elderly persons with visual impairments and perceived security in the performance of daily occupations: a randomized study”, *American Journal of Occupational Therapy*, Vol. 56 No. 3, pp. 322-330.

Ivanoff, S.D. (1998), “Development of a health education programme for the elderly with age-related macular degeneration: a focus group”, *Patient Education and Counseling,* Vol. 34, No. 1, pp. 63-73.

Ivanoff, S.D., Sjostrand, J., Klepp, K.I., Lind, L.A. and Lindqvist, L. (1996), “Planning a health education programme for the elderly visually impaired person - a focus group study”, *Disability and Rehabilitation*, Vol. 18, No. 10, pp. 515-522.

Javed, K. (1993), *Survey into the Needs of Visually Impaired Asians*, Association of Blind Asians, London.

Jinks, M.J., Evenson, L.M. and Duncan, S. (2001), “Prescription label and container preferences in a geriatric population”, *Journal of Geriatric Drug Therapy*, Vol. 5 No. 2, pp. 55-76.

Jones, R., Pearson, J., McGregor, S., Cawsey, A., Barrett, A., Craig, N., Atkinson, J.M., Harper, W., Gilmore Harper, W. and McEwan, J. (1999), Randomised trial of personalised computer based information for cancer patients, *British Medical Journal,* Vol. 319 No. 7219, pp. 1241-7.

Jones, R.B., Pearson, J., Cawsey, A.J., Bental, D., Barrett, A., White, J., White C.A., and Gilmour, W.H. (2006), “Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial”, *British Medical Journal*, Vol. 332 No. 7547, pp. 942-8.

Kiesler, D.J. and Auerbach, S.M. (2006), “Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions”, *Patient Education and Counseling*, Vol. 61 No. 3, pp. 19-341.

Lacey, A. and Luff, D. (2001), *Trent Focus for Research and Development in Primary Care: An Introduction to Qualitative Data Analysis*, Trent Focus, Nottingham, UK.

Landes, R. and Popay, J. (1993), “'My sight is poor, but I'm getting on now': the health and social care needs of older people with vision problems”, *Health and Social Care in the Community,* Vol. 1 No. 6, pp. 325-335.

Lincoln, Y.S. and Guba, E.G. (1985), *Naturalistic Inquiry,* Sage Publications, Beverly Hills, CA.

Marsland, D., Leoussi, A.S. and Norcross, P. (1994), “Disability abated: audio-cassettes for the visually impaired”, *Journal of the Royal Society of Health*, Vol. 114, No. 1, pp. 29-32.

Masey, H. (1997), *The Support and Information Needs of Newly Registered Visually Impaired People,* Research Report, RNIB Corporate Planning and Evaluation, London.

Mays, N, and Pope, C. (1995), “Rigour and qualitative research”, *British Medical Journal*, Vol. 311, No. 6997, pp. 109-112.

Miles, M.B. and Hubermann A.M. (1994), *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd edition, Sage Publications, London.

Moore, J.E., Armstrong G.K., Lamb, A.M. and Giesen, J.M. (1992), “Information and referral needs of persons with partial sight”, *Journal of Rehabilitation Administration*, Vol. 16, No. 3, pp. 84-100.

Moore, N. (2002), “A model of social information need”, *Journal of Information Science,* Vol. 28 No. 4, pp. 297-303.

Moore, N. (2000), *The Information Needs of Visually Impaired People: A Review of Research*, RNIB, London.

National Statistics (2003), *The National Statistics Socio-economic Classification (NS-SEC),* National Statistics, London, available at: http://www.statistics.gov.uk/methods_quality/ns_sec/ (accessed 20 August 2010).

Nzegwu, F. (2004), *The Experiences of Visually Impaired Users of the NHS*, The Guide Dogs for the Blind Association, London.

Papadopoulos, R. and Scanlon, K. (2002), *The needs of Visually Impaired People Resident in the London Borough of Enfield, Report No. 4, The Final Report*, Research Centre for Transcultural Studies in Health, Middlesex University, London.

Parette, H.P., VanBiervliet, A. and Holbrook, M.C. (1990), “Technological needs of visually impaired and blind persons in Arkansas”, *Journal of Visual Impairment and Blindness*, Vol. 84, No. 10, pp. 534-538.

Petterson, T. (1994), “How readable are the hospital information leaflets available to elderly patients?”, *Age and Ageing*, Vol. 23, No. 1, pp.14-16.

Pope, C. and Mays, N. (1999), *Qualitative Research in Health Care*, 2nd edition, BMJ Books, London.

Resnikoff, S., Pascolini, D., Etya ale, D., Kocur, I., Pararajasegaram, R., Pokharel, G.P. and Mariotti, S.P. (2004), “Global data on visual impairment in the year 2002”, *Bulletin – World Health Organization*, Vol. 82 No. 11, pp. 844-851.

Ritchie, J. and Spencer, L. (1994), “Qualitative data analysis for applied policy research”, in Bryman A and Burgess RG (Eds.), *Analyzing Qualitative Data*, Routledge, London, pp. 173-194.

RNIB (1998), *'Ill informed'*, Campaign Report 7, Royal National Institute for the Blind (RNIB), London.

RNIB (2001), *Improving Lives: Priorities in Health and Social Care for Blind and Partially Sighted People*, Royal National Institute for the Blind, London.

RNIB (2009), Royal National Institute for the Blind web-site. http://www.rnib.org.uk/xpedio/groups/public/documents/code/InternetHome.hcsp (accessed 2 June 2009).

RNIB Cymru (2001), Accessible information services. www.rnib.org.uk/services/cymru/accessinfo.htm (accessed 11 November 2001).

Rubinstein, M.P., Currie, A.D.M., Rundstrom, M.M. and Amoaku, W.M.A. (2003), "Low vision devices and the diabetic patient", *The British Journal of Visual Impairment*, Vol. 21, pp. 3, pp. 115-117.

Schnuth, M.L. (1977), "Dental health education for the blind", *Dental Hygiene*, Vol. 51, No. 11, pp. 499-501.

The Stationery Office (1995), *Disability Discrimination Act 1995*, The Stationary Office, London.

Uslan, M.M., Eghtesadi, K. and Burton, D. (2003), "Accessibility of blood glucose monitoring systems for blind and visually impaired people", *Diabetes Technology and Therapeutics*, Vol. 5 No. 3, pp. 439-448.

Welbourne, A., Lifscitz, S., Selvin, H. and Green, R. (1983), "A comparison of the sexual learning experiences of visually impaired and sighted women", *Journal of Visual Impairment and Blindness*, Vol. 77, No. 6, pp. 256-259.

Williams, A.S. (2002), "A focus group study of accessibility and related psychosocial issues in diabetes education for people with visual impairment", *Diabetes Educator*, Vol. 28 No. 6, pp. 999-1008.

Williams, M. (1993), *The Needs of Visually Impaired People Region of Strathclyde, Scotland*, Glasgow and West of Scotland Society for the Blind, Glasgow.

Wilson, T.D. (1999), "Models in information behaviour research", *Journal of Documentation*, Vol. 55 No. 3, pp. 249-270.

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Figure 1. The major interview themes and sub-themes

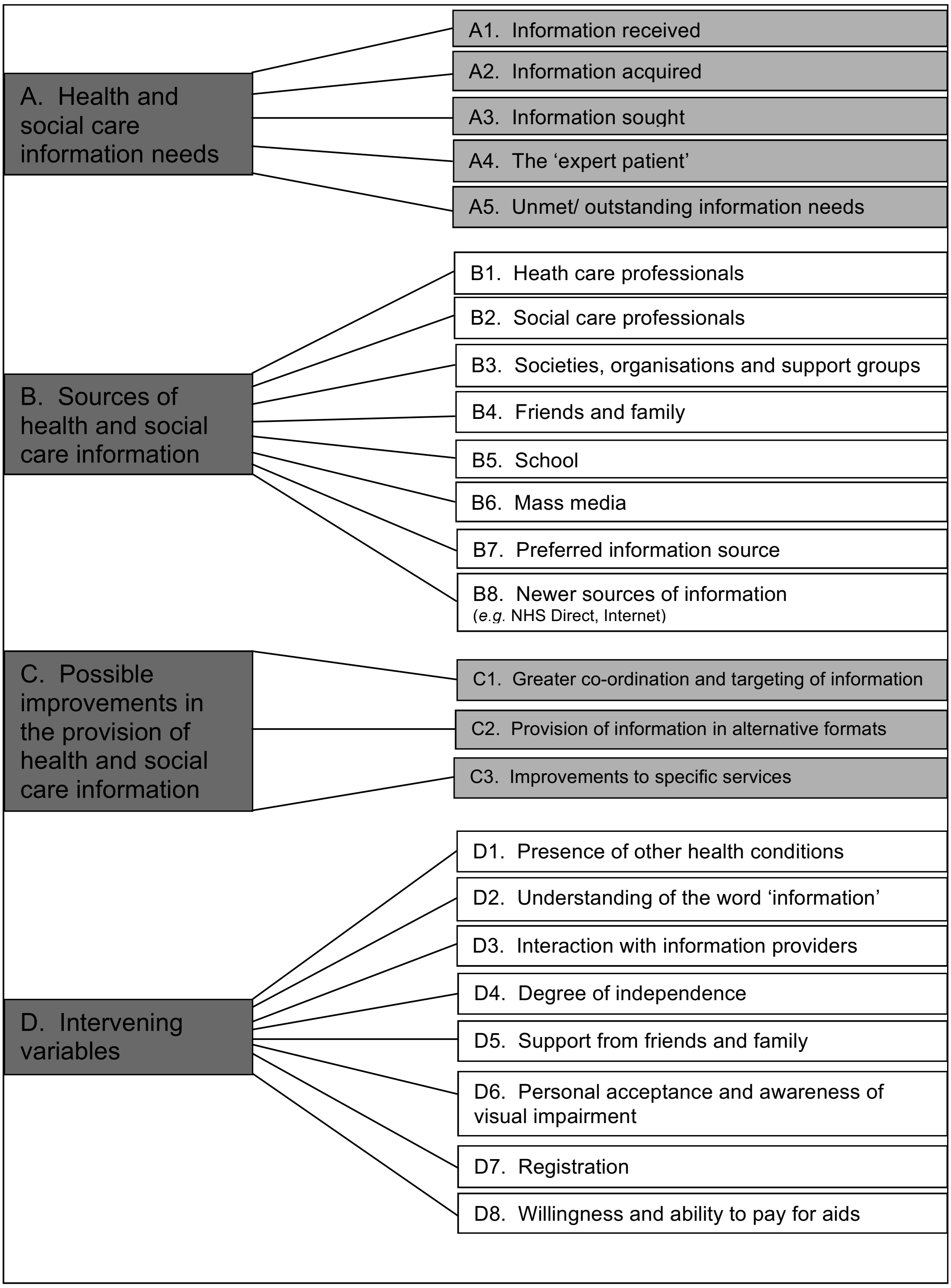

Table I. The major demographic characteristics of the interview participants.

(**A** refers to people with an **a**ge-related visual impairment; **B** refers to people with a visual impairment since **b**irth or early childhood.)

	Total (N = 31)	**A** (N = 17)	**B** (N = 14)
Age			
Mean age (years)	62.42	80.24	40.79
Age range (years)	19 - 91	58 - 91	19 - 77
Gender			
Male	15	6	9
Female	16	11	5
Ethnic origin			
White - British	30	17	13
Asian British – Pakistani	1	0	1
Marital status			
Married	12	6	6
Widowed	12	11	1
Single	7	0	7
Co-habitation status			
Live with spouse	13	9	3
Live alone	12	6	7
Live with parent(s)	4	0	4
Live with child(ren)	2	2	0
Employment status			
Employed (including self-employed)	3	0	3
Retired	17	16	1
Unemployed	9	1	8
Student	2	0	2
Socio-economic status *			
1. Higher managerial and professional occupations	1	1	0
2. Lower managerial and professional occupations	2	1	1
3. Intermediate occupations	5	4	1
4. Small employers and own account workers	1	0	1
5. Lower supervisory and technical occupations	0	0	0
6. Semi-routine occupations	2	1	1
7. Routine occupations	5	4	1
8. Never worked and long-term unemployed	10	1	9
Occupations not stated or inadequately described	5	5	0

*Based on National Statistics (2003)

Table II. The characteristics of the interview participants in terms of their visual impairment

(**A** refers to people with an **a**ge-related visual impairment; **B** refers to people with a visual impairment since **b**irth or early childhood.)

	Total (N = 31)	**A** (N = 17)	**B** (N = 14)
Type of visual impairment			
Age-related macular degeneration	7	7	0
Age-related macular degeneration, plus cataracts	5	5	0
Glaucoma	5	2	3
Unknown	3	3	0
Cataracts alone	2	0	2
Glaucoma, plus cataracts	1	0	1
Retinitis pigmentosa	1	0	1
Nystagmus	1	0	1
Congenital macular dystrophy	1	0	1
Damaged optic nerve at birth	1	0	1
Born with no eyes	1	0	1
Myopia	1	0	1
Albinism	1	0	1
Trauma (car accident)	1	0	1
Length of visual impairment			
Less than 12 months	3	3	0
1-4 years	5	5	0
5-10 years	5	5	0
More than 10 years	18	4	14
Registration status			
Registered	27	13	14
[Registered blind]	*[18]*	*[5]*	*[13]*
[Registered partially sighted]	*[9]*	*[8]*	*[1]*
Not registered	3	3	0
[Not eligible]	*[2]*	*[2]*	*[0]*
[Unaware of registration process]	*[1]*	*[1]*	*[0]*
Unknown	1	1	0