

The Health and Social Care Information Needs and Behaviour of People with a Visual Impairment

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ABSTRACT

Background and purpose: There are currently almost two million people with a visual impairment in the United Kingdom, many of whom also experience other health conditions and/or disabilities. People with visual impairments are, therefore, often regular users of health and social care services. Information has an important role in helping support and improve people's health and social care. The purpose of this thesis was, therefore, to address an identified knowledge gap and undertake an in-depth study of the health and social care information needs and behaviour of people with a visual impairment.

Design/ methodology/ approach: The research consisted of four interconnected studies: an interview study with 17 people with an age-related visual impairment and 14 people with a visual impairment since birth or early childhood; an audio diary study with seven older visually impaired people; a survey of managers of local societies for the blind and partially sighted; and an evaluation of the active involvement of visually impaired people in the design of this research.

Findings: As a result of this research we now have a detailed understanding of the health and social care information needs of two groups of visually impaired people, in particular the types of information they require; the information sources they use, such as local societies for the blind and partially sighted; what factors potentially affect their information behaviour; the possible role of newer information sources, such as NHS Direct and the Internet; as well as the extent to which two established information models (Wilson, 1999 and Moore, 2002) can explain their information behaviour.

Originality/ value: This research, the first of its kind, substantially increases our knowledge of the health and social care information needs and behaviour of visually impaired people by employing novel approaches, such as the adoption of audio diaries as a research method, and involving visually impaired people directly in the design of the research.

Keywords: Visually impaired people; information needs; human information behaviour; health needs; social care needs; qualitative research.

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RELATED PUBLICATIONS AND PRESENTATIONS

Journal articles (refereed)

- 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 Special Issue on Human Information Behavior*, **63**(1), 9-32.
- 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*, **12**(1), 1-24

Journal articles (non-refereed)

- Beverley, C. (2005a). "Health and social care information needs research study: can you help?" *Side View*, the Macular Disease Society Newsletter, **74**(Winter 2005), 33.
- Beverley, C. (2006a). "Health and social care information needs research study". *MDS Digest*, the Journal of the Macular Disease Society, **2006**, 78.

Conference presentations

- Beverley, C., Bath, P.A. and Barber, R. (2005). "The health and social care information needs of people with a visual impairment". Poster presented at *Getting Your Message Across - Presenting to the Public, UK Grad Conference, 26 May 2005, University of Leeds*.
- Beverley, C., Bath, P.A. and Barber, R. (2006a). "The health and social care information needs of people with a visual impairment". Poster abstract in *Proceedings of the 11th International Symposium on Health Information Management Research (ISHIMR), 14-16 July 2006, Nova Scotia, Canada*.
- Beverley, C., Bath, P.A. and Barber, R. (2006b). "Involving visually impaired people in research: a case study". Poster talk at the *INVOLVE Conference, 6-7 September 2006, University of Hertfordshire*.
- Beverley, C., Bath, P.A. and Barber, R. (2006c). "The health and social care information needs of older people with a visual impairment: a pilot audio diary study". Paper

presented at the *British Society of Gerontology, 35th Annual Scientific Meeting, 7-9 September 2006, University of Wales, Bangor.*

Beverley, C., Bath, P.A. and Barber, R. (2007). "The role of local societies for the blind and partially sighted in meeting the information needs of visually impaired people". Poster abstract in *Proceedings of the 12th International Symposium on Health Information Management Research (ISHIMR), 18-20 July 2007, Sheffield.*

Seminars and informal talks

Beverley, C. (2005b). "The health and social care information needs of people with a visual impairment". Seminar given as part of the *University of Sheffield Department of Information Studies Seminar Series, 18 January 2005.*

Beverley, C. (2005c). "The health and social care information needs of people with a visual impairment". Talk given to the *South Lakes Society for the Blind (SLSB), 14 December 2005, Kendal.*

Beverley, C. (2006b). "The health and social care information needs of people with a visual impairment". Talk given to the *Sheffield Macular Disease Society, 1 June 2006, Sheffield.*

CHAPTER 1. INTRODUCTION AND BACKGROUND

The thesis starts by giving a brief introduction to and justification for the research topic, as well as highlights the researcher's motivation for investigating the health and social care information needs and behaviour of visually impaired people.

1.1 Background to and Importance of the Research

There are currently an estimated 161 million people with a visual impairment worldwide (Resnikoff *et al.*, 2004), including about two million people in the United Kingdom (UK), which corresponds to 1.8% of the population (European Blind Union, 2002a; Keil, 2008). The actual figure is likely to be substantially more due to wide ranging definitions of 'visual impairment' and the fact that only one third of visually impaired people are formally registered as being blind or partially sighted (Robinson *et al.*, 1994; Bunce *et al.*, 1998). Visual impairment is one of the most age-related disabilities: within the UK, the majority of people with visual impairments are aged over 64 years of age (RNIB, 1998a). Population trends suggest that the situation will worsen in the future, with the number of older people with a visual impairment predicted to increase exponentially (Stein and Kalache, 1999; Resnikoff *et al.*, 2004). Visual impairment places a huge economic burden on society; for example, in 2002, it was estimated that annual costs for those registered blind or partially sighted in England alone ranged from £1.4 billion to £2.9 billion (Ethical Strategies Limited, 2003).

There are many different types and causes of visual impairment. In developed countries, such as the UK, most impaired vision is caused by age-related conditions (Evans, 1995), such as macular degeneration, glaucoma, and cataract. The different types and causes of visual impairment are described in more detail in Section 2.3.4. Visual impairment is also frequently experienced along with another permanent disability or illness, such as arthritis, heart conditions, mobility problems, diabetes and/or hearing impairment (Bruce *et al.*, 1991). People with visual impairments, therefore, tend to be more regular users of health and social care services than the general population (RNIB, 1998b).

Information has an important role to play in helping support and improve people's health and social care, as illustrated by the following quote taken from the 1998 NHS information strategy:

"Patients and their carers are increasingly interested to learn more about their condition, the treatments they are undergoing, and the likely outcomes, as well as needing information to support them in day-to-day living with long-term conditions and in helping them access health and social care services." (NHS Executive, 1998).

Evidence suggests that information provision is an important feature of health services: as far back as 1988, Hall *et al.*, for example, found that giving patients more information was associated with increased patient satisfaction, better compliance and better recall and understanding of medical conditions. Typically, an individual facing health and social care problems has cognitive (*i.e.*, the need for factual information about prevention, detection and/or treatment) and affective (*i.e.*, the need for information that will aid in dealing with the condition emotionally) information needs (Wilson and Walsh, 1996). Information needs, therefore, tend to arise when a person recognises a gap in his/her state of knowledge and wishes to resolve that anomaly (Nicholas, 2000). However, information is not always accessible and does not always meet the needs of specific groups, such as people with visual impairments. As a result, there are now initiatives to reduce inequalities in health and social care and to make services accessible to everyone (Office of Public Sector Information, 1995; Department of Health, 1999a; ADSS, 2002).

In 2002, the Centre for Health Information Management Research (CHIMR) at the University of Sheffield undertook a systematic review on behalf of the Welsh Assembly Government of the literature relating to the health information needs of visually impaired people (Beverley *et al.*, 2002; Beverley *et al.*, 2004). The major finding of this review, described in more detail in Section 2.7, was that there was no high quality research in this field, yet it was recognised as a key area requiring urgent research attention. The review also identified various assumptions inherent in the existing research; for example, that visually impaired people simply required the same information as totally sighted people, but in different formats (*e.g.*, Braille, large print, *etc.*). The basis of this thesis was, therefore, to test these assumptions and address this knowledge gap by undertaking an in-depth study examining the health and social care information needs and behaviour of people with a visual impairment.

1.2 Aims and Objectives of the Research

The overall aim of the research was to examine the health and social care information needs and behaviour of visually impaired people. More specifically, the objectives of the research were:

- To obtain a greater understanding of the health and social care information needs and behaviour of two groups of people with a visual impairment: people with an age-related visual impairment and people with a visual impairment since birth or early childhood (Chapters 4 and 5).
- To investigate the extent to which these information needs are currently being met, particularly by local societies for the blind and partially sighted (Chapter 6).
- To explore the strengths and weaknesses of using audio diaries as a research method with older visually impaired people (Chapter 5).
- To evaluate the impact of the active involvement of visually impaired people in this research on the design and outcomes of this research (Chapter 7).

1.3 Reasons and Motivation for Undertaking the Research

There were two main reasons for undertaking this research. Firstly, at an academic level, the initial literature review undertaken for the Welsh Assembly Government (Beverley *et al.*, 2002; Beverley *et al.*, 2004) clearly identified a gap in the knowledge base in this field and the need for high quality research into the health and social care information needs of people with a visual impairment. Secondly, at a personal level, the researcher's grandmother was diagnosed with a visual impairment (age-related macular degeneration (AMD) and cataracts) in the late 1990s and she saw first-hand the effect this had on her grandmother's lifestyle and psychological well-being. She was, therefore, determined to find answers to specific questions her grandmother (and others) had relating to health and social care information.

1.4 What the Research Adds to the Current Knowledge Base

This research, the first in-depth study of its kind, substantially increases our knowledge and understanding of the health and social care information needs and behaviour of visually impaired people. It does this by employing novel approaches, such as the adoption of audio diaries as a research method, and involving visually impaired people directly in the design of the research. The research also clearly identifies in Chapter 9 specific implications for practice, some of which have already started to be implemented.

1.5 Research Timeline and Thesis Structure

A timeline for the research presented in this thesis is provided in Appendix A. The thesis starts by examining in detail the current literature in the field and highlights gaps in the knowledge base (Chapter 2). Chapter 3 builds on this by providing the methodological background to the research and outlines the methods employed for this research and the reasons for adopting these approaches. The first phase of the research, an interview study with two groups of visually impaired people designed to identify their information needs, is described and discussed in Chapter 4. These information needs are elaborated on in Chapter 5 which presents the findings of a small-scale audio diary study with older visually impaired people. This chapter also discusses the strengths and weaknesses of utilising audio diaries as a research method with visually impaired people. The focus of Chapter 6 is on a survey of managers of local societies for the blind and partially sighted which was undertaken in response to the findings of the interview study and audio diary study. Chapter 7 describes and analyses how visually impaired people have been directly involved in the design of this research, and relates this to current literature on public involvement in research. All the major findings from each of the individual studies are triangulated and discussed in Chapter 8, particularly within the context of two established information models (Wilson, 1999 and Moore, 2002). Finally, the implications for practice and future research emerging from this research are identified and discussed in Chapter 9.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

This chapter builds on the introduction and background to the research presented in Chapter 1 by providing a critical review of the literature relating to visual impairment and information, with specific reference to health and social care and models of information behaviour. It starts by giving a brief background to visual impairment, in particular terminology and diagnosis, types and causes of visual impairment, and health and social care services available to visually impaired people. An overview of the literature relating to information, including information needs and information behaviour, is then provided. The major models of information behaviour are presented and their potential application to this research is evaluated. The literature linking information, visually impaired people, and health and social care is then considered and the limitations of existing research are discussed. Gaps in the current knowledge base are subsequently identified, thereby providing a rationale for undertaking this research. The next section describes the literature review methods used.

2.2 Literature Review Methods

The references cited here were identified via a comprehensive and systematic literature search. Although a systematic review of the literature review *per se* was not undertaken for all aspects of this literature review, principles of systematic review methodology were adhered to where possible (NHS Centre for Reviews and Dissemination, 2001). Sensitive searches, designed for maximum recall, were employed in the major information science (*e.g.*, LISA), computer science (*e.g.*, INSPEC), health (*e.g.*, Medline, Embase, CINAHL), health-related (*e.g.*, PsycINFO, AMED), science (*e.g.*, Science Citation Index), social science (Social Science Citation Index, ASSIA, Caredata) and education (*e.g.*, ERIC) electronic bibliographic databases. In addition, a variety of 'grey literature' sources were searched, including Health Management Information Consortium (HMIC), the web sites of relevant organisations in the field (*e.g.*, Royal National Institute for the Blind, Action for Blind People) and current research registers (*e.g.*, National Research Register, Index to Theses). A combined free-text and thesaurus search strategy was utilised. A sample

search strategy used in Medline (Ovid) is provided in Appendix B. No date, study type or publication type restrictions were used. Due to resource constraints, searches were, however, restricted to English language papers.

The database searches were supplemented by a general Internet search using a standard search engine (Google). Major organisations and experts in the field were also contacted. Citations searches were conducted on key papers and the reference lists of relevant studies were checked for additional references. The searches were originally conducted in winter 2001, and subsequently repeated in the major databases every six months. Journal alerts were also set up in Zetoc to identify the most recent references.

For the references relating to the health and social care information needs of visually impaired people, a quality assessment was undertaken using established critical appraisal tools: the CRITICAL Skills Training in Appraisal for Librarians (CRISTAL) checklist (Booth, 2000) and, for surveys, a rating scale developed by Kate Thomas of the University of Sheffield Medical Care Research Unit (MCRU), based on Nelson (1999) and Gomm *et al.* (2000).

2.3 Visual Impairment

The term 'visual impairment' is used to describe a wide range of eye conditions. This section discusses the terminology used, the prevalence of some of the major eye conditions, and the different health, social care and voluntary services available to visually impaired people. The section concludes by considering the potential impact a visual impairment has on an individual's life.

2.3.1 Disability, Impairment and handicap

Until recently disability was viewed solely in terms of a medical model. This model describes the restrictions and limitations in disabled people's lives as resulting from their impairments. According to the medical model, first coined by the World Health Organisation, but subsequently assumed in the *Disability Discrimination Act 1995* (Office of Public Sector Information, 1995), 'impairment' can be defined as "*any loss or abnormality of psychological, psychological or anatomical structure or function*"; 'disability'

as “any restriction or lack of ability (resulting from an impairment) to perform in the manner or within the range considered normal for a human being”; and ‘handicap’ as “a disadvantage for a given individual (resulting from an impairment or disability) that limits or prevents the fulfilment of a role which was normal (depending on age, gender, social and cultural factors) for that individual” (World Health Organisation, 1980). This definition has been criticised because it was developed primarily by non-disabled people and implies impairment results in disability; and that there is a clear and appropriate definition of ‘normal’ (Duckett and Pratt, 2001).

In contrast, the social model, which was devised by disabled people, describes the restrictions and limitations in the lives of disabled people as resulting from environmental, attitudinal and organisational barriers within society. According to this model, ‘impairment’ refers to “*lacking part or all of a limb, or having a defective limb, or other part of the body*”, while ‘disability’ is “*the disadvantage, or restriction, caused by a contemporary social organisation, which takes no, or little account of people who have impairments and therefore excludes them from participation in the mainstream of social activities*” (Direct Payments Scotland, 2002).

There are also numerous variations on these two models which are discussed in detail by several authors, including Darling (2003), Donoghue (2003), Gabel and Peters (2004), Bolt (2005a), Bolt (2005b), and Douglas *et al.* (2007a). The International Classification of Functioning, Disability and Health (ICFDH), for example, adopt a ‘biopsychosocial’ approach drawing upon both the medical and social models (World Health Organisation, 2001a). Meanwhile, Bolt (2005a) advocates a tripartite typology consisting of ableism, disablement and impairment.

For this research, the researcher has adopted a combined medical and social model as the underlying philosophy, perhaps most akin to that of the ICFDH (World Health Organisation, 2001a). This is because, although the researcher supports the ethos of the social model, she does not have a disability herself and has always worked within medical and social care settings, where the medical model is still prevalent.

2.3.2 Visual impairment terminology and diagnosis

A wide variety of terms are used to describe visually impaired people, including blind, partially sighted, visually handicapped, visually disabled, low vision, sight impaired, print impaired, *etc.* and there is little agreement about the most appropriate terminology (Bolt, 2005a). There are also numerous definitions of visual impairment (Brodney-Folse *et al.*, 2003). According to Bruce and Baker (2001), definitions should involve the measurement of visual acuity, visual field and contrast sensitivity, linked to functional assessment. However, definitions normally incorporate an estimate of visual loss in terms of impairment (*e.g.*, measuring visual acuity of visual fields), or are measured in terms of disability, *i.e.*, the ability, or otherwise, to perform a certain task (Bruce and Baker, 2001).

The International Classification of Diseases (ICD-10), the European Blind Union (2002a) and the World Health Organisation (2001b), define 'blindness' as, "*visual acuity of less than 3/60 Snellen, or a visual acuity of between 3/60 and 6/60 Snellen and a considerable contraction of the field vision, or a visual acuity of greater than 6/60 Snellen and field contraction covering the majority of the field*". Snellen refers to the measurement on a chart comprising a series of high contrast black letters that line by line decrease in size. Normal vision is denoted by 6/6. 3/60 Snellen, therefore, means that a person can see at three metres what a totally sighted person can see at 60 metres (Richards, 2003). Individuals are registered as partially sighted if they have visual acuity of between 3/60 and 6/60 Snellen and a full field of vision, or a visual acuity of between 6/60 and 6/24 Snellen and a moderate contraction of their field of vision, or a visual acuity of up to 6/18 Snellen, or even better, with a gross field defect (European Blind Union, 2002a).

It is evident from the literature (*e.g.*, Duckett and Pratt, 2001; Deal, 2003), however, that some people with visual impairments are opposed to being grouped together as "visually impaired people" because it recognises people's similarities rather than differences, and emphasises a person's impairment, rather than their ability. Similarly, Bolt's (2005a) hierarchical categorisation suggested that terminology like blindness and the blind which denotes only visual impairment should be rejected in favour of more progressive terminology, such as visual impairment and people with impaired vision, that recognises a continuum of visual impairment as advocated by the social model of disability.

2.3.3 Prevalence of visual impairment

There are considerable variations in the prevalence rates reported for visual impairment (e.g., Wormald *et al.*, 1992; Reidy *et al.*, 1998; Tate *et al.*, 2005; Hendershot *et al.*, 2006). These differences appear to stem from the different definitions of impairment used, and different measurement techniques (Landes and Popay, 1993; Tate *et al.*, 2005). For example, Resnikoff *et al.* (2004) estimated that there were in excess of 161 million people with a visual impairment worldwide in 2002, of which about 37 million were blind. These estimates were based on the best available evidence derived from recent studies (e.g., Pascolini *et al.*, 2004) and used the ICD-10: H54 (9) definitions of low vision and blindness. In contrast, the World Health Organisation estimated in 2001 that there were 44.8 million people worldwide with a visual impairment (Cunningham *et al.*, 2001; World Health Organisation, 2001a), with a further 135 million people classified as being visually disabled (World Health Organisation, 2001b). As the population ages and the incidence and prevalence in key underlying causes of sight loss increase, so sight loss is expected to become even more prevalent in the future (Bosanquet and Mehta, 2008). Foster and Gilbert (2000), for example, estimated that there will be a net increase of 1-2 million blind people each year worldwide, whereas Bosanquet and Mehta (2008) reported that there will be a doubling in the number of blind individuals from the year 2000 to 2020.

In 2008, there were an estimated 2 million visually impaired people in the UK (Bosanquet and Mehta, 2008; Keil, 2008). An even greater figure, based on two national prevalence studies (van der Pols *et al.*, 2000; Evans *et al.*, 2002), was reported by Charles (2008): between 1.6 million and 2.2 million people aged 65 years and over in the UK have a visual acuity ranging from mild to serious levels of visual impairment. Only some of these people are actually registered sight impaired, however. For example, there were only 307,000 people on the blind or partially sighted register in England on the 31st March 2006 (Department of Health, 2006a). Official registers, therefore, underestimate the number of people with a visual impairment by at least a factor of three (Bruce *et al.*, 1991; Gregory, 1996; European Blind Union, 2002a; Barry and Murray, 2005). Even higher levels of non-registration have been found by other authors, including Robinson *et al.* (1994) and Bunce *et al.* (1998).

A RNIB survey showed that, compared with the general population, the age distribution of the registrably visually impaired population was heavily skewed towards the older age

groups (Bruce *et al.*, 1991). For example, in 1991, 66% of visually impaired people were aged 75 or over, compared to just 8% of the general population (Bruce *et al.*, 1991). Similar figures were reported by the European Blind Union (2002a), Resnikoff *et al.* (2004) and Department of Health (2006a). This situation is likely to worsen as life expectancy continues to increase (Stein and Kalache, 1999; Taylor and Keeffe, 2001; Resnikoff *et al.*, 2004). Resnikoff *et al.* (2004) also found that the burden of visual impairment was not distributed uniformly; for example, women have a significantly higher risk of developing a visual impairment than men.

2.3.4 Types, causes and treatment of visual impairment

There are many different types and causes of visual impairment (Ghafour, 1983; Gregory, 1996) and, as Godber (1999) and Beverley *et al.* (2004) noted, it is inappropriate to treat visually impaired people as a 'single homogenous group'. Interestingly, Douglas *et al.* (2006) estimated that 23% of the visually impaired population did not know, or were unsure of, the name of the eye condition responsible for their visual impairment. Evidence suggest that over 50% of sight loss is due to preventable or treatable causes, and this is most marked in the older population, where it is estimated to be between 50% and 70% (Bosanquet and Mehta, 2008). A Cochrane review (Smeeth and Iliffe, 2006) found, however, that mass screening of older people for visual impairment did not result in improvements in vision.

Visual impairments can be classified in a number of ways; the most common approach being by diagnostic category. However, visual impairments can also be distinguished in terms of their time of onset (Bruce *et al.*, 1991), *i.e.*, onset at birth, sudden loss, or gradual onset. Brophy and Craven (1999) adopted an alternative approach to considering visual impairment, based on the main types of effects: total blindness, central vision loss, peripheral vision loss (*i.e.*, tunnel vision), and a generally lowered visual acuity, but without field losses.

In developed countries, most impaired vision is caused by age-related conditions (Evans, 1995), such as macular degeneration, as described in more detail below; glaucoma, the name given to a group of eye conditions in which the optic nerve is damaged at the point where it leaves the eye (Royal College of Ophthalmologists, 2002a); and cataract, an

opacity or clouding of the lens (RNIB, 2003a). Among people of working age, diabetes is a major cause of visual impairment (Evans, 1995). In contrast, worldwide, cataract is the leading cause of visual impairment, followed by glaucoma, age-related macular degeneration (AMD) and diabetic retinopathy (Resnikoff *et al.*, 2004). This is illustrated by a new global initiative being set up by the World Health Organisation and international non-governmental organisations (NGOs), called *VISION 2020 – The Right to Sight*, to tackle five priority areas, including cataracts. The rest of this section considers the two main types of visual impairment (age-related visual impairment and visual impairment since birth or early childhood) which form the focus of this thesis.

2.3.4.1 Age-related macular degeneration (AMD)

As stated earlier, most impaired vision in developed countries is caused by age-related conditions, in particular macular degeneration, hence the researcher decided to study the information needs of this group of visually impaired people in more detail as part of this research. AMD is the late stage of age related maculopathy, a degenerative disease of the macula, the centre of the retina (Arnold and Heriot, 2007). It affects central vision and usually involves both eyes, although they may not be affected at the same time or to the same degree (Royal College of Ophthalmologists, 2002b). There are two types of AMD: dry AMD, also known as non-exudative or atrophic AMD; and wet AMD, also known as exudative or disciform degeneration. Dry AMD is more common, affecting between 85% and 90% of people with AMD (Bressler *et al.*, 1988; Royal College of Ophthalmologists, 2002b). It generally progresses slowly over many years, and the time to blindness is highly variable, usually 5-10 years (Arnold and Heriot, 2007). Wet AMD is more sight threatening (Arnold and Heriot, 2007) and occurs when tiny new blood vessels grow between the retina and the back of the eye (Royal College of Ophthalmologists, 2002b). Macular degeneration co-exists with other eye conditions (*e.g.*, cataract) in about a quarter of the visually impaired population in the UK (Royal College of Ophthalmologists, 2002b).

Various research studies and guidelines exist relating to the diagnosis, treatment (*e.g.*, American Optometric Association, 1997; Royal College of Ophthalmologists, 2000; American Academy of Ophthalmology, 2001; NICE, 2003) and risk factors (*e.g.*, Silvestri *et al.*, 1994; Seddon *et al.*, 1996; Smith *et al.*, 1996; Evans and Henshaw, 1999) associated with AMD. According to a review of the best available evidence published in *Clinical*

Evidence in 2007, only a few interventions (*e.g.*, photodynamic therapy (PDT) with verteporfin; antiangiogenesis treatment using pegaptanib; and antiangiogenesis treatment using ranibizumab) are known to be effective in the treatment of AMD (Arnold and Heriot, 2007). More recently, in August 2008, the National Institute for Health and Clinical Excellence (NICE) published guidance on the use of pegaptanib (macugen) and ranibizumab (lucentis) for the treatment of wet AMD (NICE, 2008).

2.3.4.2 Visual impairment since birth or early childhood

Impaired vision can also onset at birth or early childhood. For example, Evans (1995) found that congenital and hereditary conditions accounted for nearly 30% of 'blind' certifications in England and Wales. In developed countries, the most common causes of visual problems in children are: retinopathy of prematurity (ROP); congenital problems, such as cataracts; genetic diseases; amblyopia, commonly referred to as 'lazy eye'; and strabismus, also known as 'crossed eyes' (Waldrop, 2001). The researcher thought that it would be important to also explore the information needs of a group of visually impaired people who had had a visual impairment since birth and/or early childhood, and to compare these needs with those of people with an age-related visual impairment. By doing so, it was hoped that it would be possible to provide some evidence for and/or against the notion of visually impaired people being a 'single homogenous group' (Godber, 1999).

2.3.5 Co-morbidity associated with visual impairment

Visual impairment is frequently experienced along with another permanent disability or illness; for example, it has been estimated that 67% of visually impaired adults (Bruce *et al.*, 1991) and 56% of visually impaired children (European Blind Union, 2002a) have one or more permanent illnesses or disabilities (excluding hearing problems). The most prevalent conditions are arthritis, heart conditions, mobility problems and diabetes (European Blind Union, 2002a). The balance ability of older people with visual impairments has also been found to be lower than in people without a visual impairment, thereby indicating the possible increased risk of falls and resultant injury (Lee *et al.*, 2003). In addition, 35% of visually impaired people experience some difficulty in hearing normal speech (European Blind Union, 2002a). In Britain, for example, an estimated 250,000 people have a dual sensory impairment (Gregory, 1996). This has led to national

government guidance being published on health and social care services for older people with dual sensory loss (Department of Health, 1997), and on the social care of deaf-blind children and adults (Department of Health, 2001a).

According to Capella-McDonnall (2007) visually impaired people are substantially more likely to report poor, fair, or worsening health than are people who are sighted. People with visual impairments, therefore, tend to be more regular users of health and social care services than the general population (RNIB, 1998b), and have a wide range of information needs relating to other health conditions, as well as their visual impairment. However, it has been argued by some authors, such as Levy (1997), that people with a visual impairment and one or more additional disabilities, particularly those with a learning disability, are often denied access to specialist services for the visually impaired. This is not only because their sight loss is not identified, but also because there are limited specialist visual impairment workers.

2.3.6 The registration process

In England, each local authority (either a Social Services department or a local voluntary visual impairment society) keeps a confidential register of blind and partially sighted people living in its area (RNIB, 2002a). There is no legal requirement for visually impaired people to register (Gregory, 1996; Richards, 2003) and several authors (*e.g.*, Barry and Murray, 2005) have highlighted some of the problems associated with registration. However, there are a various benefits of registration, including the entitlement to claim certain financial benefits and concessions. The registration process in England and Wales was changed in September 2005 (Department of Health, 2007) in an attempt to separate out social care needs and registration. The form BD8 (Robinson *et al.*, 1994; RNIB, 2002a; The EyeCare Trust, 2003) was replaced by a new Certificate of Vision Impairment (CVI). This certificate is signed by a consultant ophthalmologist to certify patients as being severely sight impaired (blind) or sight impaired (partially sighted) and passed on to the relevant council with social service responsibilities (or their agents) to formally register someone (Department of Health, 2007). A Letter of Visual Impairment (LVI), or self-referral letter, is issued by an optician. An optician or GP can refer someone onto a hospital eye clinic using a Referral of Vision Impaired Patient (RVI) and they may subsequently alert social care organisations.

2.3.7 Health and social care services for visually impaired people

A wide variety of organisations provide services to visually impaired people (Brophy and Craven, 1999). In terms of health and social care, visually impaired people are generally in contact with three main services: the health service (NHS and private sector), social care, formerly referred to as Social Services (either Adult Social Care or Children's Services), and voluntary organisations.

Health services are provided by a wide range of professionals, including general practitioners (GPs), dispensing opticians, optometrists (also known as ophthalmic opticians), ophthalmic nurses, ophthalmic medical practitioners, and ophthalmologists (RNIB, 2002b). These health professionals are mainly concerned with the diagnosis and treatment of visual impairment. The changing health environment and how visual impairment services fit into the new NHS landscape is discussed by Billington (2006). The NHS Eyecare Services Programme, for example, has recently been set up as part of the NHS Improvement Strategy to develop and improve national eye care services, in particular relating to four conditions: cataract, glaucoma, AMD, and low vision (McLeod *et al.*, 2006; Mehta, 2007). This programme has issued standards for low vision services which relate to design, referral and assessment; information; service improvement, monitoring and evaluation; training; and communication (Barnshaw *et al.*, 2007). These standards attempt to address the problems of existing low vision services identified by McLaughlan *et al.* (2006), that is, such services are often fragmented, difficult to access and lack a holistic, multi-disciplinary approach.

Social care services provided to visually impaired people vary across the country. For example, in some areas, care is provided by a general social worker, whereas in other areas there are dedicated mobility and rehabilitation officers for visually impaired people, sometimes called ROVIs (RNIB, 2002b). Elsewhere certain social services are contracted out to other organisations, such as local societies for the blind (these are discussed in more detail in Section 2.3.8). Social care organisations are generally concerned with meeting the rehabilitation and support needs of visually impaired people. Guidance on *Fair Access to Care Services* (FACS) for adults with sight problems was issued by the Department of Health in 2002. Under FACS, each person's eligibility to receive social care services is established after a personal assessment to determine whether their needs are "critical", "substantial", "moderate", or "low" (Improving Lives Coalition, 2005).

The approach to delivering health and social care services has recently been challenged by the publication of the Department of Health's White Paper entitled *Our Health, Our Care, Our Say* (Department of Health, 2006b). This emphasises the importance of preventative work and calls for stronger links with the voluntary and community sectors to encourage local capacity building. These sectors have traditionally been seen as the main providers of social care for people with visual impairments (Willis, 2005). In 2007, The Guide Dogs for the Blind Association (GDBA) launched a consultation paper on the future of rehabilitation services for visually impaired adults in England called *Independence and Well-Being in Sight* (GDBA, 2007). This includes reference to the recurring themes of recent national Government green and white papers, in particular, informed choice, personalisation, working together, prevention and an emphasis on outcomes. Running alongside this, VISION 2020 UK have recently launched the first *UK Vision Strategy* (RNIB, 2007; RNIB, 2008) which has three main aims: to improve the eye health of people in the UK; eliminate avoidable sight loss and deliver excellent support to those with a visual impairment; and to enhance the inclusion, participation and independence of blind and partially sighted people.

2.3.8 Local societies for the blind and partially sighted

In addition to various national organisations, such as the Royal National Institute for the Blind (RNIB), Action for Blind People and the Macular Disease Society, there are numerous independent local societies for the blind and partially sighted within the UK. These local societies provide practical support, advice and information to sight impaired individuals, and their family and friends (NALSVI, 2006). According to NALSVI (2006), there is no typical local society for the blind, with each differing in their size, outreach, funding source, and in the range of services that they offer. However, in general terms, local societies provide a wide range of services, including giving information on aids, adaptations and equipment, advising on benefits entitlements, providing home visiting or befriending services, running social clubs and special interest groups, and organising holidays. Many, although not all, local voluntary organisations for blind and partially sighted people are members of NALSVI (National Association of Local Societies for Visually Impaired People).

It has been argued that local societies have lost their focus in recent years (*e.g.*, The Smith and Williamson Group, 1997; Lomas, 2000). In order to address this, The Smith and Williamson Group (1997) proposed six possible pathways for local societies which consisted of different levels of integration with the RNIB. In contrast, Lomas (2000) focused on four main directions: demography, in particular the magnitude of the growth of the older visually impaired population; separating out services for younger visually impaired people whose rehabilitation and social care needs differ greatly from those of older people; expanding the contribution of volunteers from the community; and placing a greater emphasis on outcomes, *i.e.*, demonstrating the impact local society services have on the health and well-being of service users. However, it is clear from anecdotal evidence that local societies have a valuable role to play in meeting the needs of visually impaired people.

2.3.9 Low vision aids, adaptations and equipment

Low vision aids (*e.g.*, magnifiers, telescopes and electronic aids, such as Closed Circuit Television, CCTV) have been shown to be an effective means of providing visual rehabilitation (Margrain, 2000). However, a recent systematic review of reading aids for adults with low vision, completed by the Cochrane Eyes and Vision Group (Brodney-Folse *et al.*, 2003; Virgili and Acosta, 2006), only identified nine studies which evaluated the different types of low vision aids and the conclusion of this review was that further research was needed on the comparison of different aids. In addition, various models of low vision aid provision exist across the country involving ophthalmologists, optometrists and low vision therapists, and the availability of aids is uneven (Lomas, 1998). Patient acceptance and usage of these aids is also variable; often due to inadequate training being provided (Birchall, 1999; Casten *et al.*, 2005). The Department of Health established Low Vision Services Committees at a local level in an attempt to address the fragmentation of current services (Fong, 2000). An evaluation of the implementation of these committees by Gibson *et al.* (2005) found that, although there was evidence that considerable progress had been made, there were a number of outstanding challenges, including engaging with key stakeholders, such as Primary Care Trusts (PCTs), and widening the extent of service user involvement.

Numerous other devices and adaptations exist which can help visually impaired people (Kleinbeck, 2006). These include talking watches and clocks, liquid level indicators, *etc.* Burden *et al.* (1999), for example, found that devices, such as speaking metres, fixed dose syringes, click count syringes, syringe carriers, magnifying lenses, and dose guide cards, as well as cartridge filled pens and pre-filled pens, could help diabetic visually impaired people to inject or monitor themselves.

2.3.10 The impact of having a visual impairment

Visual impairment has a considerable effect not only on the individual affected, but also on society. At an individual level, having a visual impairment tends to affect a person's lifestyle and emotional status, as illustrated by a national survey of the needs and lifestyles of the needs and lifestyles of visually impaired adults in the UK (National Statistics, 2001). Similarly, Bruce *et al.* (1991) found that over 90% of all visually impaired people surveyed experienced difficulty with at least one area of daily living skills, such as personal care and domestic tasks. In terms of independent living skills, 'preparing a meal' and 'household cleaning' are often cited as the most challenging tasks (Douglas *et al.*, 2006). Many authors (*e.g.*, Kirtley, 1975; Allen, 1989; Church, 1999; Brennan and Cardinali, 2000; Crossland and Culham, 2000; Fong, 2000; Burmedi *et al.*, 2002a; Burmedi *et al.*, 2002b; Papadopoulos and Scanlon, 2002a; Goodrich, 2003; Moore and Miller, 2003; Percival and Hanson, 2005) have examined in more detail the effects, in particular the psychological impact, of having a visual impairment. The considerable effect of having a visual impairment on a person's quality of life should not be underestimated: Bosanquet and Mehta (2008) reported that very severe AMD can result in a 63% decrement in quality of life, a decrease similar to that associated with having a stroke.

The process of adjusting to visual loss has been shown to typically involve similar emotions to those of the recently bereaved; that is, shock (and/or denial), depression and acceptance (Crossland and Culham, 2000). The length and intensity of each phase varies between individuals, depending on personal circumstances, the cause of the sight loss and the support available to the individual (Masey, 1997; Crossland and Culham, 2000). For example, Papadopoulos and Scanlon (2002a) found that participants who experienced visual impairment since birth or early childhood and those who experienced a gradual loss of sight were better able to cope with, and adjust to, their visual impairment than those

participants who experienced a sudden loss of sight. Friends and family are thought to play an important role in individuals' acceptance of their visual impairment, as illustrated by Bruce *et al.* (2007)'s exploration of blind and partially sighted people's perceptions of their inclusion by family and friends.

Visual impairment also places a huge economic burden on society; for example, in 2002 it was estimated that annual costs for those registered blind or partially sighted in England alone ranged from £1.4 billion to £2.9 billion (Ethical Strategies Limited, 2003). Similarly in 1997, the World Health Organisation conservatively estimated that the total cost of blindness to society in the United States of America was US \$4.1 billion per year (World Health Organisation, 1997). These costs include social benefits and productivity losses, but exclude condition specific treatment costs and overlook the fact that many visually impaired people are not actually registered. The actual costs to society are, therefore, likely to be considerably more, as illustrated by a study by Hopley *et al.*, (2003) which measured the economic impact of visual impairment from AMD in Australia. This study not only described the current burden of disease, but also predicted the changes in the burden of disease over time, and evaluated the efficiency of different interventions.

2.4 Information

The *Oxford English Dictionary* defines information as (Simpson and Weiner, 1989):

1. *The action of informing. The action of telling or fact of being told something.*
2. *That of which one is apprised or told: intelligence, news.*

As Case (2002) notes, this nominal definition reveals at least one important distinction: the term 'information' may be used to indicate a process (informing), or a kind of message (news). However, it is evident that information has been used to denote various overlapping concepts, rather than neatly distinct phenomena (Case, 2002). For example, a review by Schement and Ruben (1993) identified over 20 definitions for the term (Case, 2002). Although there is no single agreed typology (Case, 2002), many authors (*e.g.*, Buckland, 1991; McCreadie and Rice, 1999a; McCreadie and Rice, 1999b) identify three different types of information. Dervin (1977), for example, makes the distinction between objective, external information which attempts to describe reality; subjective, internal information which represents a picture or cognitive map of reality; and sense-making

information which reflects the procedures and behaviours that allow us to understand the world and usually to act on that understanding as well.

Related to the concept of information are the terms 'data' and 'knowledge' (Machlup, 1983; Case, 2002). 'Data' can be thought of as the 'raw' type of information, whilst 'knowledge' refers to information that has been sifted, organised and understood by a human brain (Case, 2002). The three concepts have tended to be treated as a hierarchy, with data at the bottom and knowledge at the top (Case, 2002). Several higher-order concepts also build upon the concept of information. These include: 'information need', 'information behaviour', 'information seeking', 'information source' and 'information use' (Case, 2002). The following sections look at some of these concepts in more detail.

2.4.1 Information needs

Information needs arise when an individual recognises a gap in his or her state of knowledge and wishes to resolve that anomaly (Nicholas, 2000; Case 2002). In the health context, Tester (1992) defines information need as, "*the lack of appropriate information on which to base choices that could lead to benefits or services that may improve people's well-being*". It can be argued that most people do not have information needs *per se*, but rather that they experience a problem or difficulty or are under some pressure, and these needs may be met, or partially met, by obtaining and then applying that information (Nicholas, 2000). Information needs, therefore, arise out of a desire to meet one or more of the three basic human needs (Nicholas, 2000):

1. Physiological needs, *i.e.*, the need for food, shelter, *etc.*
2. Psychological needs, *i.e.*, the need for domination, security, *etc.*
3. Cognitive needs, *i.e.*, the need to plan, learn a skill, *etc.*

It is clear that people do not always know what their information needs are, *i.e.*, they have dormant (or unrecognised) information needs (Nicholas, 2000). They do not know they have an information gap, nor are they aware that there is information out there that could be of help. It is only when they are exposed to the relevant information that the needs are recognised. Similarly, individuals may have a number of unexpressed information needs, *i.e.*, they may be aware of their information needs, but do nothing about them, either because they cannot, or will not, for example, due to barriers, obstacles, *etc.* (Nicholas,

2000). According to some authors (e.g., Wilson, 1981; Belkin and Vickery, 1985), the notion of an information need is an unrealistic concept: most information needs could be said to be accounted for by more general needs, and cannot actually be observed. In fact people often refer to information needs when they are actually referring to information wants, demands or use (Nicholas, 2000), where 'information wants' refers to the information that an individual would like to have, and 'information demands' are requests for information that an individual believes they want.

2.4.2 Information behaviour

Several authors (e.g., Wilson, 1999; Case, 2002; Spink and Cole, 2004) now seem to prefer using the term 'information behaviour'. This encompasses information seeking, foraging, retrieving, organising and use (Spink and Cole, 2004). Wilson (1981, 1997, 2000), for example, believes that while researchers concern themselves over a definition for information needs, much of the time they are really concerned with information seeking behaviours. Information behaviour may be defined as the more general field of investigation (Wilson, 1999), encompassing information seeking as well as the totality of other unintentional or passive behaviours, such as encountering information, as well as purposive behaviours that do not involve seeking, such as actively avoiding information (Case, 2002). Information seeking and information searching are thus sub-sets of the wider information behaviour field; the former being concerned with the variety of methods people employ to discover, and gain access to information resources; and the latter with interactions between the information user (with or without an intermediary) and information systems (Wilson, 1999). The definition adopted in this thesis is based on Wilson's (2000) definition of information behaviour:

"the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given."
(Wilson, 2000: 49).

Finally in this section, it is useful to note that since starting this thesis, Ford (2005) has made the distinction between information behaviour and knowledge behaviour. The need for knowledge is broader than an information need in that the former entails defining the nature of the sought-for knowledge, as opposed to the type and nature of the information

which may be used to generate it. Knowledge behaviour, therefore, refers to the realisation and specification of a knowledge need, along with the evaluation of information behaviour in terms of its contribution to satisfying the information need (Ford, 2005).

2.4.3 Models of information behaviour

Numerous theories and models of information behaviour have emerged in the literature, particularly since the 1970s. These theories and models can be thought of as simplified versions of reality (Case, 2002). According to Wilson (1999: 250):

"A model may be described as a framework for thinking about a problem and may evolve into a statement of the relationships among propositions. Most models in the general field of information behaviour are of the former variety: they are statements, often in the form of diagrams, that attempt to describe an information seeking activity, the cases and consequences of that activity, or the relationships among stages in information seeking behaviour".

Information models range from the purely pragmatic and descriptive, such as a flow chart, to formal models that combine mathematical and pictorial logics (Case, 2002). Each approach to studying information behaviour has its strengths and weaknesses in terms of its ability to conceptualise the wide range of specific dimensions or aspects of information behaviour (Spink and Cole, 2006) and no one approach seems to completely explain information behaviours.

Research into models of information seeking behaviour up until the mid-1970s was generally concerned with system use rather than behaviour and consisted of 'document-focused studies' (Wilson, 2000). Since the 1980s, there has been a shift towards a more 'person-centred' approach, illustrated by the work of Ellis, Dervin, Kuhlthau and Wilson (Craven and Brophy, 2003). Case (2002), for example, compared five of the major information behaviour models at the time: Krikelas (1983), Johnson (1997), Leckie *et al.* (1996), Wilson (1981), and Wilson and Walsh (1996). All five of these models attempt to depict and explain a sequence of behaviour by referring to relevant variables, rather than merely indicating a sequence of events. They all also indicate something about information needs and sources, something which is omitted from some of the other major information models, such as Ellis (Ellis, 1989; Ellis *et al.*, 1993) and Kuhlthau (1991).

Another model of information behaviour is Dervin's sense-making theory (Dervin, 1983). However, this is really a set of assumptions, a theoretic perspective, a methodological approach, a set of research methods, and a practice designed to cope with information (Wilson, 1999). Sense-making is implemented in terms of four consistent elements: a 'situation' which defines the context in which information problems arise; a 'gap' which identifies the difference between the contextual situation and the desired outcome; 'outcome', *i.e.*, the consequence of the sense-making process; and a 'bridge', *i.e.*, some means of closing the gap between the situation and outcome. More recently, Spink and Cole (2006) examined three interdisciplinary approaches to how people seek information: information seeking-sense-making (Savolainen, 1995), information foraging (Pirulli and Card, 1999), and problem-solution perspective on information seeking. In response to this review, they proposed a fourth information approach based on information use theory, as well as devised an initial integrated model of these different approaches.

2.4.4 Application of models of information behavior to health and social care

Many of the established information models listed above (*e.g.*, Wilson, 1981; Dervin, 1983; Krikelas, 1983; Ellis, 1989; Kuhlthau, 1991; Ellis *et al.*, 1993; Johnson, 1997; Leckie *et al.*, 1996; Wilson and Walsh, 1996) have been applied to information seeking in the context of health and social care (*e.g.*, Miller, 1987; Buckland and Dawson, 1989; Johnson and Meischke, 1993). Other models which have been used in this context include Miller's monitoring and blunting theory (Miller, 1987), Buckland and Dawson's (1989) household claiming behaviour model and Johnson and Meischke's (1993) model of information seeking. Although not an information model *per se*, Attfield *et al.* (2006) undertook a study of the information seeking behaviour by NHS patients which explored motivational triggers for information needs. They found that patients initiated information seeking to assess whether they needed clinical intervention, in preparation for the patient-doctor consultation, and to verify diagnosis or treatment stemming from that consultation. The study also revealed that having confidence in health practitioners was a key motivation for information seeking. However, studies on information needs and seeking patterns of patients have generally focused on people who seek information, with only a passing explanation of the behaviour of people who do not want information (Baker, 1995).

Miller's (1987) model is based on the assumption that when individuals are threatened with an aversive event (*e.g.*, stress), they differ in how they deal with information about it. 'Monitors', for example, prefer a high information input before a stressful event and suffer less physiological arousal when they have information, whereas 'blunters' distract themselves from and psychologically blunt threatening cues. Buckland and Dawson's (1989) model of household claiming behaviour has useful parallels with health information seeking behaviour (Buckland, 1994). However, the approach has not been developed or adopted since the 1980s. Finally, Johnson and Meischke's (1993) model suggests that health-related factors (demographic, direct experience, salience and beliefs) provide the motive force for information seeking actions which are shaped by information carrier factors (characters and utility). This model has been incorporated into Wilson's revised model.

2.4.5 Application of models of information behavior to visually impaired people

Several information models have the potential to be applied to the health and social care information behaviour of people with visual impairments. Savolainen (1995) and others, for example, have examined the situational aspect of information seeking-sense-making in everyday life information seeking. Spink and Cole (2006) summarised the relative value attributed to information from insiders (*i.e.*, people from the small world in which the individual lives) and outsiders (*i.e.*, people from the larger world or society). It is possible to consider people with a visual impairment as having contact with insiders, such as other visually impaired people (*e.g.*, groups of people who have been blind since birth), as well as outsiders, such as health care professionals or social care service providers. However, the diversity of visual impairments makes it difficult to determine whether different sources or providers of information are insiders, outsiders, or neither of these, and, therefore, whether it is appropriate to consider the world of people with a visual impairment as separate from society.

Pirolli and Card's (1999) model of information foraging proposed that human information foragers assess the potential value of an information source in relation to other possible sources using "information scent". The forager sniffing for information based on this scent may lead the forager to pursue that information source with a stronger scent at the expense of others. Superficially this model is potentially attractive in trying to understand

the information behaviours of people with a visual impairment, in that it uses scent and the sense of smell as a metaphor for information seeking and people with an impairment in one sense may develop heightened awareness in their other senses. However, the idea of information foraging was developed in relation to Internet searching and is likely, at least to some extent, to be dependent on visual cues which may not be readily available or accessible to people with a visual impairment.

Wilson's (1999) revised model of information behaviour does appear, however, to have the potential to be applied to the information behaviour of people with visual impairments. Wilson's problem-solving perspective on information seeking, discussed in greater detail below in Section 2.4.6, is based on the premise that information seeking commences with a perceived need for information by the user, and that the user identifies and then defines this need, before seeking information to meet the need and solve the problem. It is possible to imagine a person with a visual impairment, who has either been blind since birth or has experienced impaired vision in later life, having information gaps, which they try to resolve through information seeking. Wilson's model is, therefore, likely to be helpful in understanding the information behaviour of visually impaired people.

Although several studies have been conducted on the generic information needs of visually impaired people (*e.g.*, Williamson, 1995; Astbrink, 1996; RNIB, 1998b; Williamson, 1998; Oppenheim and Selby, 1999), Williamson *et al.* (2000) identified "*no major study of the information needs and information seeking behaviour of this group of people (sight impaired citizens)*". In terms of information behaviour models, Williamson and Schauder (1999) used Williamson's (1995, 1998) model as the basis of a conceptual framework for a study of information seeking by visually impaired people in Australia. This model took into account Dervin's sense making theory (Dervin, 1983), Wilson's information seeking behaviour (Wilson and Walsh, 1996) and the ecological theory of aging (Birren and Birren, 1990). However, the focus of this and other more recent research (*e.g.*, Carey and Stringer, 2000; Goble *et al.*, 2000; Nielsen, 2000; Craven, 2003; Craven and Brophy, 2003) has been on Internet use and access by visually impaired people, rather than their broader information needs and behaviour.

However, a model of social information need has emerged in response to a review of the research literature into the information needs of visually impaired people (Moore, 2000;

Moore, 2002). This model has been used by the RNIB as a tool for analysing information provision, and has been advocated for use in analysing the scope and nature of the social information needs of other groups of people (Moore, 2002). Moore's (2002) model clearly has the potential to be applied to the health and social care information behaviour of people with visual impairments, and it is, therefore, considered in more detail below in Section 2.4.7.

2.4.6 Wilson's revised model of information behaviour

Wilson has developed a series of macro-models and models of gross information seeking behaviour which attempt to integrate various information models (Wilson, 1981, 1994, 1997, 1999). Wilson's models were not specifically developed with the information needs of visually impaired people in mind but were based on generic needs in general situations and have the potential to be applied to the information behaviour of people with visual impairments.

Wilson's models were based on two main propositions: first, that information need is not a primary need, but a secondary need that arises out of needs of a more basic kind; and, second, that in the effort to discover information to satisfy a need, the enquirer is likely to meet with barriers of different kinds (Wilson, 1981). The revised Wilson (1999) model, as shown in Figure 1, embodied a set of questions about information behaviour: why some need prompt information seeking more so than others ('stress/ coping theory'); why some sources of information are used more than others ('risk/ reward theory'); and why people may, or may not, pursue a goal successfully, based on their perceptions of their own efficacy ('social learning theory'). In addition, Wilson identified a number of 'intervening variables' which may be involved in an individual's information behaviour. These variables included psychological predispositions, demographic background, factors related to an individual's social role, environmental variables (e.g., available resources), and characteristics of the sources (e.g., accessibility and credibility). Wilson's revised model also recognised that there are different types of active and passive search behaviours.

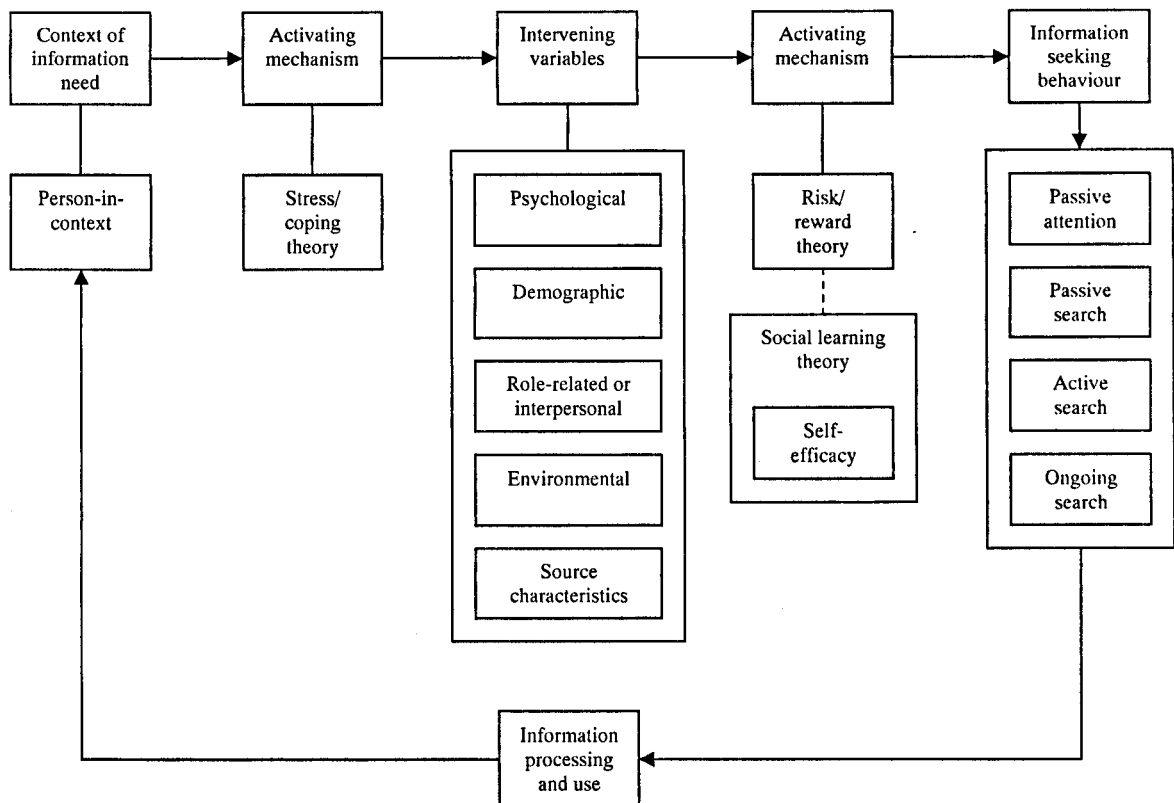


Figure 1. A revised general model of information behaviour (adapted from Wilson and Walsh, 1999; explained in Wilson, 1997)

2.4.7 Moore's model of social information need

In essence, Moore (2002) described social information as having six different dimensions:

1. Function (why do people need information?)
2. Form (what kind of information do people need?)
3. Clusters (what do people need information about?)
4. Agents (who initiates the information activity?)
5. Users (how do needs differ between different groups of people?)
6. Mechanisms (which mechanisms can be used to meet information needs?)

According to Moore (2002), people need social information to support them in two roles they play as members of society: as "citizens" and as "consumers". The same can be said

of health and social care information and this is indeed advocated in the 1998 NHS information strategy (NHS Executive, 1998).

Moore reported that people need information to help them build up an understanding of the world in which they live ('environmental scanning') which means that people need to be able to get answers to specific questions that bother them ('answers to questions'). However, Moore acknowledged that information alone was not always enough to trigger action and that, in an ideal world; there would be a continuum of information provision ranging from information through advice to advocacy (Moore, 2002). Moore's model focused on three different initiators of the information activity: information 'seekers', information 'providers' and information 'processors'.

Two different approaches to considering information needs were described by Moore (2002). The first was based on different levels of need; for example, Maslow (1968) identified five levels: physiological needs (*e.g.*, food, water, warmth and protection); safety needs; love, affection and belongingness needs; esteem needs; and self-actualisation needs (the additional benefits that accrue to self-esteem through doing something that the individual feels to be worthwhile). The second approach was based on Tester (1992)'s assumption that information needs were associated with major life events.

Moore (2000) found, however, that it was not possible to identify the actual hierarchy of information needs that were experienced by visually impaired people. Instead, he identified eight main clusters of need: the condition, its treatment and likely outcome; benefits and money; general health; aids and equipment; housing and accommodation; mobility; services and facilities; employment, education and training.

Moore's model provided important insights into the social information needs and behaviour of people with a visual impairment. However, it was based on an analysis of research reporting these needs and not on primary research into these needs. It was, therefore, deemed valuable for this thesis to verify the applicability of Moore's model in a separate sample of visually impaired people.

In conclusion, Moore's model of social information need (Moore, 2002) appears to be the model most applicable to the information behaviour of visually impaired people, mainly

because it was developed directly in response to a literature review of the information needs of visually impaired people. For the reasons outlined in Section 2.4.6, it was also decided to analyse the data and interpret the findings presented in this thesis using Wilson's revised model (Wilson, 1999) in order to establish the extent to which this *generic* model could be applied *specifically* to the information behaviour of visually impaired people. The results of this analysis are presented in Chapter 8.

2.5 Information and Visually Impaired People

The importance of making information accessible for visually impaired people is highlighted in recent legislation, such as *The Disability Discrimination Act* (Office of Public Sector Information, 1995), as well as related documents, such as *The United Nations Standard Rules for the Equalisation of Opportunities for Disabled People* (Gregory, 1996), the *European Blind Union Information Access Principles and Guidelines* (European Blind Union, 2002b); and the *National Standards of Social Care for Visually Impaired Adults* (ADSS, 2002). Service providers now have to make "reasonable adjustments" for disabled people (RNIB, 2003b). For visually impaired people, information must be made available in 'alternative formats', such as large print, Braille, Moon, computer disk, audio tape, telephone services, spoken or verbal announcements, accessible Web sites, tactile maps, etc. (Gregory, 1996). Section 2.5.1 considers these alternative formats in more detail. It is evident from the literature that the focus of existing research has been on alternative formats for visually impaired people, rather than their explicit needs relating to other aspects of information provision, such as content, timing and available support mechanisms (Beverley *et al.*, 2004).

2.5.1 Alternative formats

A survey by Bruce *et al.* (1991) found that 48% of visually impaired adults were unable to read standard print. There is no single preferred information format for visually impaired people and guidance exists on producing accessible information (*e.g.*, RNIB, 2001a). Simply using a larger and clearer print can help many partially sighted people (Brophy and Craven, 1999). However, some people can only read these using a low vision aid so large quantities of information should be avoided in this format. Braille, a series of raised dots which can be read by touch, is appropriate for some visually impaired people. There are

two types of Braille: grade one which presents the alphabet letter by letter and includes punctuation; and grade two which is a condensed version where common words and letter sequences are abbreviated (Gregory, 1996). However, only approximately 2% of the visually impaired population can read Braille (Gregory, 1996). Another format is Moon, which is a simple tactile alphabet, based on the traditional Roman alphabet. It is often favoured by older people because it requires less sensitivity in the finger tips (Brophy and Craven, 1999). However, there are only approximately 1,000 Moon readers in Britain (Gregory, 1996).

Special consideration needs to be given when providing information to people who have a dual sensory impairment. Accessible formats include British Sign Language (BSL), a series of hand gestures and facial expressions, and fingerspelling, which is used to indicate words, such as proper names, which do not have a dedicated sign. However, some people who have acquired sensory impairments later on in life find it difficult to learn new methods of communication (Gregory, 1996).

Simply providing information in alternative formats may not be sufficient for some visually impaired people. For example, information may need to be provided in different languages as well (Gregory, 1996). In addition, approximately 7.3 million adults in Britain have literacy problems and 1 million have some degree of learning difficulty, so information must be in plain language and as concise as possible (Gregory, 1996).

2.5.2 The Internet and assistive technologies

Recent advances in Information and Communication Technologies (ICT), in particular assistive technologies, such as screen magnification software, screen synthesisers, screen readers, large screen monitors, CCTV, Braille embossers, character recognition software and speech inputters, have the potential to provide information in more accessible formats to visually impaired people (Gregory, 1996; Williamson *et al.*, 2001; Wales Council for the Blind, 2002). Web content accessibility guidelines, *e.g.*, Bobby and World Wide Web Consortium Web Accessibility Initiative (W3C/ WAI), have helped in this respect (Jones and Tedd, 2003; Owen, 2003). There is, therefore, an increasing body of literature relating to ICT for visually impaired people (*e.g.*, Kinnell and Creaser, 2000; Coard, 2002; Gill, 2002; Fruchterman, 2003; Goodrich, 2003; Nemeč *et al.*, 2003; Wolffe *et*

al., 2003; Huang *et al.*, 2004; Gibson, 2004; Lewis, 2004; Gill, 2005). Zúnica and Clemente (2007), for example, found that for Spanish speaking blind and partially sighted people the Internet was a very valuable tool as it allowed them to access written information in an autonomous and instantaneous manner and to communicate with others through individual email and discussion lists.

However, it appears that Internet access and computer use by people with visual impairments is substantially (30%) less than that for people with no disabilities (Gerber and Kirchner, 2001; Douglas *et al.*, 2007a). Similarly, Capel *et al.* (2007) reported that, although in 2003-4, 12.1 million UK households had Internet access at home, only 12% of over 65 years olds had used the Internet compared to 58% of the adult population as a whole. Many web sites also still do not meet the necessary requirements (Ross, 2002; Murphy *et al.*, 2007; Lüchtenberg *et al.*, 2008). Lüchtenberg *et al.* (2008), for example, found that only 18% of the 139 web sites containing medical information studied achieved the desired WAI standards. Douglas *et al.* (2007a) discovered, in a study of more than 1,000 visually impaired people, that many visually impaired people wanted to use computers, but were prevented from doing so by a variety of individual-based barriers (*e.g.*, problems related to their visual impairment, confidence, time and priority/motivation), and social-based barriers (*e.g.*, cost, availability of equipment, accessibility of equipment, *etc.*). These findings are similar to those reported elsewhere, *e.g.*, Sinks and King (1998), Williamson *et al.* (2001), and Murphy *et al.* (2007).

2.6 Health and Social Care Information

There is a widespread belief that providing health and social care information is beneficial. Providing information to patients has been shown to: increase satisfaction and reduce complaints; increase adherence to treatment; better recall and understanding of conditions; increase self-care and self-management behaviours; promote adaptive coping; reduce psychological distress, particularly anxiety; and facilitate involvement in the decision making process (Hall *et al.*, 1988; Fallowfield, 2001; Payne, 2002; Kinnersley *et al.*, 2008).

The recent NHS White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006b), published after the primary research presented in this thesis was undertaken, introduced the concept of an “information prescription”:

“The information prescription will be given to people using services and their carers by health and social care professionals (for example, GPs, social workers and district nurses) to signpost people to further information and advice to help them take care of their own condition.” (Department of Health, 2002b)

According to the Department of Health (2006b), by 2008, everyone with a long term condition should routinely receive information about their condition and, where possible, receive peer and other self care support through networks. An initial evaluation of 20 pilot information prescription sites (Office for Public Management, 2008) found that three quarters of service users felt more confident in asking questions about their condition as a result of receiving information; two-thirds of patients felt more in control of what was happening with their condition; and half of service users thought that it had helped to improve their care.

2.6.1 Definitions of health and social care information

There are very few explicit definitions of ‘health’ and ‘social care’. The national Government’s recent drive to integrate health and social care services (*e.g.*, Pollock *et al.*, 2003; Leichsenring, 2004; Department of Health, 2006b) may help to explain this. However, ADSS (2002) and Walter *et al.* (2004) both provide definitions of social care. Social care can be thought of as:

“... care which meets a person’s common human needs and gives them quality of life. It does not include the type of care provided by trained nursing or medical staff.” (ADSS, 2002)

For the purpose of this thesis, health and social care information can be thought of as any information relating to the health and well-being of a person, *i.e.*, in line with the Department of Health’s *Our Health, Our Care, Our Say* White Paper (Department of Health, 2006b). It, therefore, concerns information about the medical condition (diagnosis, treatments, *etc.*), general health promotion, rehabilitation, as well as a person’s general social care needs, such as relating to housing, employment and leisure activities. This definition is adopted because it is evident that the distinction between health and social care is often not made by an individual, and that this artificial separation between these

two areas can be confusing and divisive, both for service users and professionals (Lewis, 2001; Minford, 2001; Young, 2006).

2.6.2 Sources of health and social care information

People obtain their information about health and social care from a variety of sources, including family and friends; television and magazines, the Internet; as well as more traditional sources, such as health and social care professionals. The Internet and online-based sources of information, such as NHS Direct, are becoming important repositories of health and social care information. These sources are considered in more detail below. In terms of the type of information, Swain *et al.* (2007) found that service users most commonly required information on the following five topics: details of voluntary sector support groups; support for the family or carer(s); condition-specific services; the financial benefits available, and how to claim them; and how to comment on or complain about services.

2.6.3 Health and social care information on the Internet

Public use of the Internet for health and social care information is increasing; however, its effect on care remains unclear (Murray *et al.*, 2003). Williams *et al.* (2003), for example, examined the way the general public exploited the Internet for health information and found that people generally acted in one of the following roles: as a patient, intermediary or a professional. It is also evident that patients are now bringing Internet information to consultations with their doctors (Murray *et al.*, 2003). Interestingly, however, over a third of the doctors participating in the Murray *et al.* (2003) survey believed that a patient bringing in information made the visit less time efficient, particularly if the patient wanted something inappropriate or the doctor felt challenged.

The quality of information on the Internet is of critical importance, with the research conducted to date suggesting that most lay users do not show a healthy scepticism regarding the information provided (Williams *et al.*, 2003). However, from the doctors' perspective, although accurate, relevant information benefited a consultation, inaccurate or irrelevant information harmed health care, health outcomes and the doctor-patient relationship (Murray *et al.*, 2003).

2.6.4 NHS Direct

NHS Direct was set up in England and Wales in 1997 “to provide information and advice about health, illness and health services, to enable patients to make decisions about their health care and that of their families” (NHS Direct, 2007). An equivalent service operates in Scotland called NHS 24. NHS Direct was originally established as a 24 hour telephone helpline, but is now also provided through an Internet site (www.nhsdirect.com) and digital television. Over two million people currently access NHS Direct every month (NHS Direct, 2007) and approximately one quarter of the population in England and Wales have used NHS Direct at least once (Knowles *et al.*, 2006).

Although some people are sceptical about the value of NHS Direct, the related reports are often anecdotal and consist of letters to journals, such as the *British Medical Journal*. The research evidence on NHS Direct is actually very strong and customer satisfaction with the service is high (O’Caithan *et al.*, 2000). For example, the Medical Care Research Unit (MCRU) at the University of Sheffield has undertaken a series of evaluations of NHS Direct, particularly in the early formative years of the service (*e.g.*, Munro *et al.*, 1998; Munro *et al.*, 2000; Munro *et al.*, 2001; Munro *et al.*, 2003). In addition, O’Caithan *et al.* (2005) found in a series of interviews with NHS Direct users that NHS Direct facilitated patient empowerment by allowing patients to self care and to access health advice and services. The service was seen to offer the pre-requisites for empowerment perceived to be lacking in the wider NHS, including time, respect, listening, support and information. O’Caithan *et al.* (2005) also found that NHS Direct offered an alternative contact point for people seeking to avoid being labelled “time wasters” by other health care providers.

In contrast, early research suggested that NHS Direct had difficulty meeting call handling targets and there had been no visible effect on demand for NHS services (Munro *et al.*, 2000). Where integration of NHS Direct has taken place with existing out of hours general practice co-operatives and ambulance services, the demand for general practice consultation has, however, dropped (McKenna, 2001).

It is important to note, however, that recent research has cast doubt on the equality of access to NHS Direct. For example, Knowles *et al.* (2006) found in a population of over 15,000 people that people from poorer socioeconomic groups and those with communication difficulties were less likely to use NHS Direct than others. George (2002)

and Ullah *et al.* (2003) also suggested that men, older people, ethnic minorities and other disadvantage groups currently under-utilised the service. In contrast, David (2005) found that age *per se* was not a barrier to using NHS Direct.

Finally, in this section it is helpful to briefly mention NHS Choices which was launched as an online service in 2007 to help people make choices about their health, from lifestyle decisions, such as smoking, drinking and exercise, through to the practical aspects of funding and using NHS services. This service draws together the knowledge and expertise of NHS.UK, the National Library for Health, NHS Direct, the Information Centre for Health and Social Care, the Healthcare Commission and numerous other health and social care organisations. NHS Choices aims to give people information that will allow them to ask their doctor the right questions about their health and any treatment that they need.

2.6.5 Quality and accessibility of health and social care information

The Department of Health's current information strategy, *Better Information, Better Choices, Better Health* in 2004 (Department of Health, 2004a) stresses the importance of sharing information, decisions and responsibility and that information is fundamental to choice and making informed decisions. However, the strategy acknowledges that information is not always available, or it is sometimes not provided in an appropriate medium or language. In addition, health and social care information can be variable in quality and can even be contradictory (Department of Health, 2004a). As well as helping the NHS to meet service-wide priorities, such as improving patients' experience, greater compliance with treatment regimes, better value for money, this information strategy offers numerous potential benefits to the public, patients and carers, including better access to information delivered in an accessible format; more personalised information that is directly relevant; improved relationships and communication with health professionals; increased ability for patients to take control of their health, understand what is happening and participate more fully in decisions about their care and treatment; more good quality information that can be relied on; timely delivery of information so that the public get the right information at the right time; and information is more readily available in places where people go each day, such as supermarkets, pharmacies, libraries and community centres.

The Picker Institute has recently produced two reports for the Department of Health on assessing the quality of information to support people in making decisions about their health and health care (Coulter *et al.*, 2006) and accessing information about health and social care services (Swain *et al.*, 2007). The first report found that few health information materials included a clear presentation of the likely outcomes of treatment, a discussion of clinical controversies and uncertainties, or an understanding of the patient's decision-making role (Coulter *et al.*, 2006). The second report (Swain *et al.*, 2007) found that health professionals, who are usually the first port of call for people experiencing health problems, do not systematically or proactively provide their patients with information about accessing local services. It also emerged that there was a lack of co-ordination between information providers across geographical, sectoral and organisational boundaries, and rarely did an individual or an organisation take responsibility for providing relevant information about the entire range of services available. There was also a lack of effective signposting, with the service user being left to find the relevant information themselves from the vast array of information available. With regard to the quality of information provision, users reported that most telephone information points offered a friendly service, but did not always lead to helpful or appropriate information; most health and social care web sites contained useful information, but some were poorly designed; some telephone advice services and web sites were not updated regularly; and social care services appeared to perform better than health agencies in offering information in various formats, thus making them accessible to people with disabilities (Swain *et al.*, 2007).

Although verbal information is the mainstay of health and social care information provision, this approach enables only a limited amount of information to be given, much of which is rapidly forgotten (Raynor and Knapp, 2000). Information in written, or alternative, formats has the potential to enable patients' and/or service users to fully participate in their own health and social care, by allowing specific information to be reinforced and/or supplementary information to be introduced. However, information is not always presented in an accessible format and/or language, and/or at an appropriate time (Beverley *et al.*, 2004).

In terms of the provision of medicines information, the European Commission (EC) recently issued a directive which requires suppliers to incorporate information on medicines in formats suitable for blind and partially sighted people (Gill, 2006). It was,

therefore, surprising to find that 79% of participants in a study by Pey *et al.* (2007) still experienced difficulties reading medication labels. As noted by van Eijken *et al.* (2003) older patients, particularly those with vision loss and cognitive impairment, can be more vulnerable to the incorrect use of medication. For example, in people aged 60 years or older, non compliance with medication regimens varies from 26% to 59% (van Eijken *et al.*, 2003).

Several authors (*e.g.*, Margiotta *et al.*, 2003; Gilroy, 2005) highlight the importance of providing clear relevant information, advice and advocacy for older people, as well as the need to employ new strategies in the provision of information to older people and their carers. These authors do, however, identify various initiatives, such as *Better Government for Older People* (BGOP, 2008); *Better Care, Higher Standards* (Department of Health, 1999b); and the *National Service Framework (NSF) for Older People* (Department of Health, 2001b), which have been established to promote the well-being of older people and to involve this group of people in the development and implementation of related information.

2.6.6 Quantity and timing of health and social care information

Receiving the right information is extremely important for patients pre- and post-consultation (Attfield *et al.*, 2006) and as they move through the disease process (Ankem, 2006). However, not all patients are alike in the quantity or timing of the information they need. Many of the studies undertaken in this field relate to cancer care. Ankem (2006), for example, recently undertook a meta-analysis to study the aggregate influence of demographic and situational variables on the amount of information cancer patients needed. The results of this study suggested that younger cancer patients needed more information and patients who preferred active roles in treatment decision-making expressed greater need for information (Ankem, 2006). Interestingly, however, Ankem (2006) found that the cancer patients' gender, their education, time elapsed since diagnosis of cancer, and the stage of their illness may not be related to their information needs.

In an audit of UK cancer patients' information needs, Cox *et al.* (2006) found that cancer patients wanted to be fully informed and share decision making responsibility, but did not

report receiving sufficient information in all areas. In contrast, Leydon *et al.* (2000) concluded that patient's attitudes to cancer and their strategies for coping with their illness could constrain their wish for information and their efforts to obtain it, so, for example, while all patients in their study wanted basic information on diagnosis and treatment, not all wanted further information at all stages of their illness.

Interestingly, a recent systematic review of randomised controlled trials (Kinnersley *et al.*, 2008) found that interventions for patients before consultations produced only small benefits for patients. The authors concluded that this may be because patients and clinicians had established behaviours in previous consultations that were difficult to change, or alternatively that small increases in question asking were not sufficient to make notable changes to other outcomes.

2.6.7 Sharing of health and social care information

Sharing of information between different agencies is a key issue within the health and social care sector which underpins the recent national Government White Paper, *Our Health, Our Care, Our Say* (Department of Health, 2006b) and information strategy, *Better Information, Better Choices, Better Health* (Department of Health, 2004a). Concerns about data protection issues and security of data transfer, as well as technological constraints, often prevent the transfer of information about patients and service users to different organisations. Richardson and Asthana (2006) argue that the patterns of information sharing are affected not only by inter-professional differences in the approach taken to information sharing, but also the ways in which the professions inter-relate. The evidence base for the effective transfer of information between different agencies is growing, however. Payne *et al.* (2002), for example, found in a systematic review of the literature that the most effective strategy for transferring information was through the appointment of a 'key worker' who acted as a point of contact for workers in different settings.

2.7 Health and Social Care Information and Visually Impaired People

Despite guidance existing on the information that should be provided to visually impaired people on health and social care matters (*e.g.*, ADSS, 2002), this has generally not been developed with reference to specific research evidence. In fact, very little literature has been published on the health and social care information needs and behaviour of people with a visual impairment. The most substantial piece of work in this field was a systematic review of the health information needs of visually impaired people (Beverley *et al.*, 2004). Of the 1,000 plus references identified, only 16 studies met the inclusion criteria for this review. The quality of reporting of these studies was noted as being generally poor, *i.e.*, it was difficult to determine the reliability and validity of the methods used. 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 (Ivanoff *et al.*, 1996; Hall *et al.*, 2000). The focus of the remaining studies was on information about visual impairment or coping with visual impairment (Moore *et al.*; 1992; Donnelly, 1997a; Donnelly, 1997b; Ahmed *et al.*, 2001) and about accessing health services, such as medication labels, appointment letters, test results and general medical information (*e.g.*, Grills and MacDonald, 1997; RNIB, 1998b; Bruce and Baker, 2001). Most of the studies identified concentrated on the format of information, and did not consider other important aspects of information, such as the content, timing and support mechanisms available.

It should be noted that Beverley *et al.* (2004)'s review had a very narrow focus and only addressed health information. A further 13 studies (Arsnow *et al.*, 1985; Biegel *et al.*, 1989; Parette *et al.*, 1990; Javed, 1993; Landes and Popay, 1993; Williams, 1993; Marsland *et al.*, 1994; Petterson, 1994; Ivanoff, 1998; RNIB, 1998a; Jinks *et al.*, 2001; RNIB, 2001b; RNIB Cymru, 2001) were identified in Beverley *et al.* (2002). These studies generally considered the more generic needs of visually impaired people and of older people, rather than their information needs *per se*. A survey of 514 older blind and partially sighted people, for example, identified four key areas of concern: unmet care and daily living needs, mobility, isolation, poverty and benefits (RNIB, 1998a). Meanwhile, Landes and Popay (1993) undertook a health needs assessment in the North West of England to investigate the general health and social care needs of older people with vision problems. In addition, Moore (2002), as described in Section 2.4.7 above, has developed

a model of social information need based on the identification of the information needs of visually impaired people (Moore, 2000).

Several studies have been published since the Beverley *et al.* (2004) review was conducted. These include studies of health information and visually impaired people (*e.g.*, Nzegwu, 2004; McLaughlan, 2006); generic support needs studies of visually impaired people which have identified the need for improved information (*e.g.*, Corcoran *et al.*, 2004; Higginbottom *et al.*, 2006; Percival and Hanson, 2007; Pey *et al.*, 2007); and generic information needs studies, particularly of older and disabled people (*e.g.*, Barrett, 2005; Larson, 2006). In addition, there have been several evaluations of health education programmes targeted at visually impaired people, such as Ivanoff *et al.*, 2002; Eklund *et al.*, 2004; Yalcinkaya and Atalay, 2006), and a collection of studies examining the additional barriers faced by visually impaired diabetic people (Allwinkle, 2002; Fox *et al.*, 2002; Williams, 2002; Rubinstein *et al.*, 2003; Uslan *et al.*, 2003; Leksell *et al.*, 2006; Williams, 2007). Rubinstein *et al.* (2003), for example, found that a high proportion of patients were reliant on others (*e.g.*, spouse and/or carer) to monitor their diabetic control and administer their medication. Meanwhile, a review by Mahoney *et al.* (2008) concluded that visual impairment may have a negative effect upon oral hygiene with many blind and partially sighted individuals having worse oral hygiene than sighted peers. Three of the most relevant studies published since the Beverley *et al.* (2004) review are described in more detail below.

In 2004, the GDBA undertook a telephone survey of the experiences of 832 visually impaired users of the NHS (Nzegwu, 2004). From this survey it was evident that in all settings (general practice, outpatient and inpatient), there was limited access to information in participants' preferred format, and participants experienced difficulties in physically accessing and navigating NHS buildings. It also emerged that participants thought that NHS staff had limited awareness of the needs of visually impaired people. Women and younger/ non-retired participants were generally less satisfied with their communication and/or quality of interaction with the health establishment. In response to the findings of this survey and a series of audits of GP surgeries, the GDBA issued guidelines for best practice for enhancing care provision for blind and partially sighted people in GP surgeries (Nzegwu, 2005). One of the key areas of these guidelines concerned "information and communication".

In another study, McLaughlan *et al.* (2006) found that while most service providers made an effort to raise awareness of their services in hospital eye clinics, gave advice during consultations, or provided posters and leaflets in their own waiting rooms, only a minority (less than one in five) provided information about their services via GP surgeries. People, therefore, usually had to be "in the system" to learn about available services. McLaughlan *et al.* (2006) concluded that little effort seemed to be made to reach those people who did not realise that their eye condition may be treatable or that support was available to help them live with sight loss.

A three year longitudinal study, undertaken on behalf of VISION 2020, and entitled Network 1000 (Corcoran *et al.*, 2004; Douglas *et al.*, 2006; Douglas *et al.*, 2007b; Douglas *et al.*, 2008) was undertaken between 2004 and 2007. Here, a panel of up to 1,000 representative visually impaired people was regularly interviewed to ascertain their changing needs and circumstances over time. Key issues which emerged were in line with the findings of Moore (2000): travel, transport and mobility; independent living skills, such as housework tasks, meal preparation, personal care and hygiene, and shopping; family support; social and emotional issues; communication and reading; counselling, emotional needs and adjustment; leisure activities; employment; agencies and user groups; sighted people's awareness of visual impairment; and attitudes of other people.

On the whole, the findings of these newer studies echo the key messages reported in the Beverley *et al.* (2004) review. In particular, the studies conducted to date stress the need for accessible health and social care information, but also the importance of providing timely emotional support and outcome-based services as a result of the loss of confidence brought about by a visual impairment (GDBA, 2007). Despite the multitude of studies examining the needs of visually impaired people, it is clear, however, that very few studies have explicitly considered the information needs and information behaviour of this group of people. The research undertaken thus far has generally regarded visually impaired people as a single homogeneous group, yet there is no evidence to support this hypothesis.

2.7.1 Limitations of existing research

Despite the apparent quantity of literature in this field, the depth and quality of existing research is of some concern and leaves many unanswered questions, some of which will be addressed by the research presented in this thesis. For instance, previous research has generally regarded visually impaired people as a uniform group, yet we know that many people with visual impairments have other health conditions and/or disabilities which will inevitably affect their information needs. There has also been a tendency to assume that people with visual impairments simply require the same health and social care information but in alternative formats. Little attention has been paid to the information content and quality, timing of the information delivery, the support mechanisms available, and the wide range of information sources available to and used by visually impaired people. These points also suggest an apparent lack of active involvement of people with visual impairments in actually designing and conducting research in this field; instead visually impaired people have been treated solely as “subjects” of research, an issue which is discussed in more detail in Section 3.9. Finally, it is clear that our understanding of the information behaviour of visually impaired people, particularly in the context of health and social care information, is limited, and existing information models have the potential to extend our knowledge further.

2.8 Conclusions and Implications for Future Research

To conclude, no in-depth study of the health and social care information behaviour of people with visual impairments has been conducted to date, yet this has been identified as an area requiring urgent research attention (Beverley *et al.*, 2004). The current approach to information provision for visually impaired people on health and social care matters has been largely unco-ordinated and the need for some high quality research to be conducted in this field is clearly evident. This literature review has identified the major gaps in the existing research which the research described here will address, by determining:

1. The major health and social care information needs of two groups of people with a visual impairment (people with an age-related visual impairment and people with a visual impairment since birth or early childhood).
2. The information sources used by visually impaired people to obtain information about health and social care matters.

3. The factors that affect the health and social care information behaviour of visually impaired people.
4. If current developments in information provision, such as NHS Direct and the Internet, can help to meet the health and social care information needs of people with a visual impairment.
5. The impact actively involving visually impaired people in this research has on the overall research design and outcomes.
6. The extent to which two established information models (Wilson, 1999 and Moore, 2002) can explain the information behaviour of visually impaired people seeking health and social care information.

The next chapter considers the methodology and specific methods used to address these key research areas.

CHAPTER 3. RESEARCH METHODOLOGY

3.1 Introduction

Having reviewed the current literature and identified the need for this research, this chapter gives an overview of and rationale for the research paradigm (Section 3.2) and methodologies (Section 3.3) underpinning this research. The chapter goes on to explain and justify the methods adopted (Section 3.4), especially the strengths of these approaches over other methods. The focus of Section 3.5 is on the analytical framework used, and in particular the theory and practical application of triangulation (Section 3.6). Section 3.7 highlights the validity and reliability issues associated with this research, and the steps taken to ensure the trustworthiness of the findings. Finally, Section 3.8 reviews in detail the evidence relating to public involvement in research. As noted in Section 2.7.1, there has been a lack of active involvement of people with visual impairments in the design and conduct of research in this field. The involvement of visually impaired people is, therefore, a major component of this research and explains the need for a detailed examination of the public involvement literature here.

3.2 Epistemology and Research Paradigm

The research reported in this thesis was conducted within a constructivist, or interpretivist, paradigm. According to Dootson (1995), a research paradigm or epistemology refers to the world view of a subject, including its underlying philosophy and the assumptions inherent in that view. Constructivism, as opposed to positivism, views the world as a constantly changing place in which individuals have varying perceptions of a given situation (Dootson, 1995). The underlying assumption is that reality is multiple, interrelated and determined within context, rather than there being a single "ultimate truth" (Dootson, 1995). Constructivism is synonymous with naturalistic research conducted within a holistic-inductive framework (Patton, 2002) and is, therefore, generally associated with qualitative research (Davis, 2000).

In contrast, positivism is concerned with absolute truth and prediction and is, therefore, generally associated with quantitative research (Davis, 2000). Researchers adopting a

positivist paradigm strive to provide explanations through the testing of scientific hypotheses (Dootson, 1995). Patton (2002) refers to this type of research as hypothetico-deductive research.

In recent years, post-positivist research has emerged (Clark, 1998). This views the world as contextually bound, with truths not necessarily being universally generalisable (Clark, 1998). However, there is considerable debate amongst authors (*e.g.*, Miles and Huberman, 1994; Denzin and Lincoln, 2000) concerning the precise definition and meaning of post-positivism. For example, many authors now believe that most post-positivists are constructivists, and stress the importance of obtaining multiple perspectives through the use of triangulation.

A constructivist approach was most appropriate for this research, because it concerned gaining a greater understanding and awareness of the health and social care information needs and behaviour of visually impaired people, rather than striving to test specific hypotheses to establish the "truth". In addition, constructivism is more in line with the 'biopsychosocial' model of disability, introduced in Section 2.3.1, and the underlying public involvement ethos of this research. This approach requires more empowering and emancipatory research methods (Beresford and Campbell, 1994; Duckett and Fryer, 1998; Moore *et al.*, 1998; Davis, 2000; Kitchen, 2000; Beresford, 2002) and relationships (Barnes, 1992; Oliver, 1992; Minkes *et al.*, 1995; McConkey, 1998), as illustrated by the following quote:

"Epistemologically, the policy of consumer involvement in research challenges the positivist position that knowledge can be developed 'at a distance' from consumers, who are treated as passive suppliers of data."
(Boote *et al.*, 2002: 222)

3.3 Research Methodology

In response to the constructivist approach, the majority of the research undertaken as part of this thesis was qualitative. Qualitative research is concerned with developing explanations of social phenomena (Hancock, 1998), whereas quantitative research tends to express data and findings in numerical, usually statistical, form. Mason (1998) elaborated on this definition: qualitative research is grounded in a philosophical position which is broadly interpretivist in the sense that it is concerned with how the social world is

interpreted, understood, experienced and produced. The real strength of qualitative research is its rich description (Glazier and Powell, 1992) and that the researcher is intimately involved in the process (Pope and Mays, 1999). These are perhaps also the main weaknesses of qualitative research; for example, the findings are often limited to a particular setting and/ or group of people and the results are potentially more subject to the researcher's personal biases.

Qualitative research was most appropriate for investigating the health and social care information needs of people with a visual impairment because the area was under-researched, as highlighted in Chapter 2. In addition, employing qualitative methods allowed issues to be explored in greater depth than would have been possible with quantitative techniques. In addition, several authors (*e.g.*, Wilson, 1981, 1994; Nicholas, 2000) have advocated the use of qualitative research methods to undertake studies of information behaviour.

It should be noted, however, that a mixed methods approach was adopted for this thesis, in that a quantitative survey, as described in Section 3.4.3 and Chapter 6, was used to supplement the qualitative research.

3.4 Research Methods

A useful distinction between methodology and methods is made by Strauss and Corbin (1998) and Silverman (2002): whereas methodology is "*a way of thinking about and studying social reality*" and refers to the choices we make about cases to study, methods of data gathering, forms of data analysis, *etc.* in the planning and executing of a research study, methods are "*a set of procedures and techniques for gathering and analysing data*" (Strauss and Corbin, 1998: 3). According to Nicholas (2000), there are four main methods for investigating information needs: interviews (individual and focus groups), questionnaires, diaries and observation. The research described in this thesis employed three main methods: individual interviews, audio diaries and a questionnaire. A justification for choosing these methods is provided below.

The above methods were selected because they enabled the views and opinions of participants to be captured in real-life situations. In addition, the majority of research

undertaken to date with visually impaired people has utilised qualitative methods, in particular individual face-to-face and telephone interviews (Landes and Popay, 1993; Duckett and Pratt, 2001). Individual qualitative approaches are generally favoured over group interviews by visually impaired people, as illustrated by none of the 30 participants in Duckett and Pratt's (2001) study stating a preference for a group interview. A consultation exercise with visually impaired people as part of this research, detailed in Chapter 7, also indicated a clear preference for individual face-to-face interviews over other methods, such as focus groups. The people involved in the consultation exercise thought that they would feel more at ease and less inhibited being interviewed individually. Of course, it could be argued that most people would prefer to be interviewed individually rather than as part of a group. However, the notion of using individual interviews also supports the argument highlighted in Chapter 2 that visually impaired people are a heterogeneous group. For example, Miller (1997) stipulated that the differences between individuals in the visually impaired population were likely to be proportionately larger than in the general population, because people with visual impairments vary widely in their strengths, aspirations, needs and levels and types of impairment. Similarly, Duckett and Pratt (2001) thought that in-depth case study approaches, designed to understand the perspectives of a small number of visually impaired people who have diverse backgrounds and interests, were more appropriate than large scale surveys. Whereas Papadopoulos and Scanlon (2002a) stress the importance of consulting with a representative group of visually impaired people, Duckett and Pratt (2001) believed that an 'unrepresentative' sample of visually impaired research participants (participants who are prepared to speak up on visual impairment issues) should be sought.

There are a few examples of quantitative research being undertaken with visually impaired people, although this has generally been by structured questionnaires or telephone interviews (*e.g.*, RNIB, 1998b). This may be because many people with a visual impairment are likely to find it difficult to read and complete postal or electronic questionnaires, even in large print. Several authors (*e.g.*, Craven and Brophy, 2003; Lewis, 2004) provide practical advice on surveying people with a visual impairment. This ranges from the means of delivery (*e.g.*, using telephone rather than postal questionnaires), to the design and layout of questionnaires, such as the use of alternative formats. For this research, quantitative methods were not deemed the most appropriate approach for obtaining the views of visually impaired people, mainly due to practical

constraints (e.g., the costs and availability of providing questionnaires in a variety of alternative formats), but also because of the benefits of the qualitative methods described above. However, a quantitative survey of managers of local societies for the blind and partially sighted was undertaken, as described in Chapter 6. Quantitative research was most appropriate in this case because the survey of local society managers was designed to answer a series of 'what' and 'how many' type questions with a large number of respondents, thereby allowing the production of results that could be demonstrated to be rigorous and generalisable (Fox *et al.*, 2001).

The rest of this section considers each of the three main methods used for this research in more detail: qualitative interviews, audio diaries and quantitative surveys.

3.4.1 Qualitative interviews

Individual face-to-face and telephone interviews were undertaken with two groups of visually impaired people. According to Mason (1998), the term 'qualitative interviewing' refers to in-depth, semi-structured forms of interviewing. There are two main forms of qualitative interviews: the interview guide approach and the standardised open-ended interview (Patton, 2002). Each approach has its strengths and weaknesses; for example, the interview topic guide enables interviews to remain fairly conversational and situational, but the interviewer's flexibility to sequence and word questions can result in different responses being obtained from different perspectives (Patton, 2002). The interviews undertaken as part of this research were semi-structured and utilised a topic guide. This enabled the relatively inexperienced researcher to stay focused. Further details about the approach adopted can be found in Chapter 4.

3.4.2 Audio diaries

In addition to undertaking qualitative interviews with visually impaired people, a small sample of older visually impaired people was also asked to keep an audio diary of their information needs as part of this research. The diary method involves participants making a narrative record of events, activities or thoughts about a particular topic or issue (Elliott, 1997; Bowling, 2002). Bowling (2002) identified three main approaches to diary keeping: a diary about a particular ongoing issue (such as a 'health diary', or a 'growing old diary'); a

log of daily activities; and a diary-interview (Zimmerman and Wider, 1977). For this research, the latter approach was used. This is because conducting interviews after the diaries allowed the internal consistency of participants' accounts to be checked and omissions to be filled. Diaries can be unstructured (or unsolicited), simply asking someone to record an item when something occurs (*e.g.*, a symptom of a health condition), or structured (solicited) logging, whereby the diary is completed on a regular basis, according to a series of instructions (Jones, 2000; Bowling, 2002). A semi-structured approach was adopted for this research, where participants were encouraged to record a diary entry every day.

The diary method was used for this research because of the variety of benefits it offers over other methods (Morse and Field, 1995; Johnson and Bytheway, 2001). For example, diaries provide a way of gaining access to a set of events or processes that cannot be observed because they take place in private and may already have occurred (Mason, 1998). Participants tend to be less constrained by diaries, unless they are heavily unstructured (Bowling, 2002), and the approach can be useful in highlighting creative solutions to problems (Papadopoulos and Scanlon, 2002b). In addition, several authors (*e.g.*, Conrath *et al.*, 1983; Corti, 1993; Bowling, 2002) highlight how diaries are generally less affected by recall bias and so can be a valuable check on the reliability of the information collected retrospectively by other methods, such as interviews. Adopting such a method was also in line with the public involvement ethos of this research, as described in Section 3.8, as demonstrated by Elliot (1997) finding that people making diaries felt that they were collaborators in, rather than "subjects" of, the research.

Despite their potential value, diaries are not used widely (Elliot, 1997). This may be because of the biases introduced by participants' social interests and personal prejudices (Seale, 1998). Diaries also place a great deal of responsibility on, and commitment from, the participants (Robson, 1993), and non- or partial completion of diaries is a major problem (Bowling, 2002).

There are, however, several examples of written diaries being used in the health and social care literature (*e.g.*, Elliott, 1997). Traditional written diary methods pose various barriers to visually impaired people, such as participants not being able to see where to make diary entries. Audio diaries, whereby participants record their diary onto a tape,

have the potential to overcome these barriers. For example, in response to a small scale audio diary study, Papadopoulos and Scanlon (2002b) concluded that audio diaries had great potential for collecting data from people who have difficulty reading or writing. In their study, three visually impaired people documented a day in their lives, thereby giving the researchers an insight into the experiences, feelings, problems, and practical realities of people who are visually impaired. The research described in this thesis builds on this study by undertaking a more extensive investigation into the strengths and weaknesses of using audio diaries as a research method with older visually impaired people. This study is described in more detail in Chapter 5.

3.4.3 Quantitative surveys

The third main method used for this research was a quantitative survey of managers of local societies for the blind and partially sighted. The survey is probably the most commonly used research design in health and social sciences research (Mathers *et al.*, 1998). Ideally a survey of the entire population (a census) should be undertaken. However, this is rarely possible because of practical reasons and cost-effectiveness. Surveys are, therefore, usually restricted to a representative sample of the potential group that the researcher is interested in. In this case, it was, however, possible to undertake a population-based survey of all National Association of Local Societies for the Visually Impaired People (NALSVI) members.

Surveys offer various advantages over other methods: they are efficient and cost-effective, particularly if a random sample is chosen; they can cover a geographically dispersed sample; they are flexible and can easily be combined with other methods to produce richer data; and they may have ethical advantages over some other approaches, such as invasive experimental studies. Surveys do have some limitations, however, which should not be overlooked. The representativeness of a survey is dependent on a variety of factors, including the accuracy of the sampling frame used and the response rate achieved. Surveys are also not very good at explaining why people think or act as they do (Mathers *et al.*, 1998). For this reason, the findings of the quantitative survey undertaken for this research were analysed alongside the findings of the qualitative research with visually impaired people, as detailed in Chapter 8.

A postal questionnaire, as opposed to a telephone interview or electronic questionnaire was chosen as the most appropriate method for collecting the survey data for this research. The strengths and weaknesses of these different approaches are discussed by several authors, including deLeeuw and Nichols, 1996; Mavis and Brocato, 1998; Jones and Pitt, 1999; McDonald and Adam, 2003; and Beverley and Booth, 2005. For this research, a postal means of delivery was selected due to time and cost efficiencies, and because postal questionnaires were accessible and familiar to the participants. In addition, the local society addresses were readily available in the public domain, and a high response rate was anticipated due to the interest in the subject matter from participants. Although electronic questionnaires are generally cheaper and quicker to administer, and, in some cases, provide participants with greater anonymity (Houston and Fiore, 1998), not all the local societies for the blind and partially sighted had an email address and/or Internet access and, therefore, this approach would exclude some societies from taking part.

3.5 Research Analysis

Since the majority of the research undertaken as part of this research was qualitative, the focus of this section is on qualitative data analysis. Broadly speaking there are three types of qualitative analysis: content analysis, thematic analysis and theoretical analysis (Lacey and Luff, 2001). In content analysis, the number of times a particular word or concept occurs in a narrative is simply counted. This can then be subjected to statistical analysis. In thematic analysis (sometimes called deductive analysis – Patton, 2002), units of data (*e.g.*, sentences or paragraphs) referring to a concept are given a particular code, extracted and examined in more detail in order to form new and refined themes. Finally, theoretical analysis (sometimes called inductive analysis – Patton, 2002), such as grounded theory, involves the testing of emergent theories against existing theories in the literature or further analysis of the data. Ritchie *et al.* (2005) instead advocate a hierarchy of qualitative analysis: descriptive accounts, typologies and explanatory accounts. Descriptive accounts involve the detection, categorisation and classification of the substantive content and dimensions of phenomena. Typologies refer to specific forms of classification that help to describe and explain the segmentation of the social world or the way that phenomena are characterised or differentiated. Finally, explanatory accounts tend to be developed at the later, or higher, stages of analysis when most of the

descriptive and typological work has been undertaken. These may derive from finding patterns of association within the data and then attempting to explain why these patterns occur or building explanations from other evidence or interrogations of the data.

For this research, thematic analysis has been used following all three levels of Ritchie *et al.*'s (2005) hierarchy. For most of the studies, the data have been analysed using a technique called "framework". Framework analysis, described in more detail below, is a relatively new approach to qualitative data analysis which has gained popularity particularly in health-related research (Lacey and Luff, 2001; Ritchie *et al.*, 2005). It offers numerous benefits over theoretical analysis, such as grounded theory, for this research, and directly follows on from undertaking a systematic review of the literature (Beverley *et al.*, 2004).

3.5.1 Framework analysis

Framework analysis was developed in the 1980s at the National Centre for Social Research in the context of applied policy research (Ritchie and Spencer, 1994; Lacey and Luff, 2001; Lathlean, 2006). It is a matrix based method for ordering and synthesising data (Ritchie *et al.*, 2005). It follows a well-defined procedure (Miles and Huberman, 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 as well (Lacey and Luff, 2001).

Framework analysis shares many features common to other forms of qualitative analysis, in particular the approach often referred to as 'thematic analysis' (Lacey and Luff, 2001). Unlike grounded theory, all data can be collected before analysis begins (Lacey and Luff, 2001). Framework analysis involves five distinct, though highly interconnected, stages (Ritchie and Spencer, 1994; Lathlean, 2006):

1. Familiarisation (*i.e.*, reading and familiarisation of the transcripts).
2. Identifying a thematic framework (which is initially heavily rooted in *a priori* issues, but subsequently guided by emergent and analytical themes).
3. Indexing (application of the thematic framework systematically to the data).

4. Charting (*i.e.*, creating charts of the data by “lifting” data from their original content and rearranging them according to themes in chart form).
5. Mapping and interpretation (*i.e.*, searching for patterns, associations, concepts, and explanations in the data).

Framework analysis offers several advantages over other forms of qualitative analysis and methodologies (Ritchie and Spencer, 1994), such as grounded theory, whereby an explanatory theory ‘emerges’ from the data through a process of rigorous and structured analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Lacey and Luff, 2001). In particular, framework analysis is grounded or generative, being heavily based in, and driven by, the original accounts and observations of participants. Framework analysis is dynamic and open to change, as well as being systematic and comprehensive. It allows easy access to, and retrieval of the original textual material, and enables associations between and within cases to be made. Finally, framework analysis is accessible because the analytic process and interpretations can be shared with others.

It should be noted, however, that some authors (*e.g.*, Pope and Mays, 1999) have concerns about the approach, claiming that it is “less academic” (Lacey and Luff, 2001) because it is not as concerned with the generation of theories, and, although it is heavily based in the original accounts of participants, the framework starts deductively from the aims and objectives already set for the study. Having said that, framework analysis is becoming more widely adopted and accepted (*e.g.*, Griffiths *et al.*, 2001; May, 2001; Chew-Graham *et al.*, 2002; Howe *et al.*, 2002; Tod *et al.*, 2002; Palfreyman *et al.*, 2003), as illustrated by an interview study exploring cancer patients’ information needs and information seeking behaviour (Leydon *et al.*, 2000). Several authors (*e.g.*, Clayton and Thorne, 2000; Jones, 2000) have also advocated the use of framework, as opposed to content, analysis to analyse diaries; a method used in this thesis.

3.6 Triangulation

In line with the constructivist approach of this research, triangulation has been used to obtain multiple perspectives (*e.g.*, Knafl and Breitmayer, 1991; Nolan and Behi, 1995; Begley, 1996) on the health and social care information needs and behaviour of people with a visual impairment. Triangulation involves the use of different methods and sources

to check the integrity of, or extend, inferences drawn from data (Ritchie and Lewis, 2003). It has been widely adopted and developed as a concept by qualitative researchers as a means of investigating the 'convergence' of both data and the conclusions derived from them (Ritchie and Lewis, 2003).

There is much debate about whether the value of triangulation is to validate qualitative evidence or whether the benefits lie in extending understanding through the use of multiple perspectives (Ritchie and Lewis, 2003). The researcher believes the latter, and has used triangulation to add breadth and depth to the analysis in order to provide a fuller picture of the health and social care information needs of visually impaired people. It should be noted, however, that some authors (*e.g.*, Bradley, 1995; Sandelowski, 1995; Clark, 1998) believe that from an ontological positivist perspective that there is no single reality or conception of the social world to ascertain and that attempting to do this through the use of multiple sources of information is futile (Ritchie and Lewis, 2003).

Various typologies of triangulation have proliferated, such as triangulation for convergence (or confirmation), and triangulation for completeness; however, it is generally agreed (*e.g.*, Denzin, 1978; Patton, 2002; Ritchie and Lewis, 2003) that there are four basic types of triangulation:

1. Methodological triangulation, where data generated by different methods (*e.g.*, qualitative and quantitative) are compared.
2. Triangulation of sources, where data from different qualitative methods (*e.g.*, interviews, observations, documented accounts) are compared.
3. Triangulation through multiple analysis, where different interviewers, observers and analysis are used to compare and check the collection and interpretation of the data.
4. Theory triangulation, where the data are looked at from different theoretical perspectives.

In this thesis, all four types of triangulation have been used. Methodological triangulation has been used in Chapter 8 to compare the findings from the qualitative studies (interview study and audio diary study), and the quantitative study (survey of local society managers). Both within-method triangulation (an integration of the findings from the questionnaire and follow-up interviews with local society managers) and between-method triangulation (a comparison of the findings from the interview study, the audio diary study,

and the survey) have been used. The qualitative data from two different sources (the interview study and audio diary study) have been combined to identify similarities and differences, and to provide a more in-depth explanation of the findings. Although the majority of the research has been undertaken by a single researcher, the interpretation of the findings has been shared and discussed with the visually impaired advisors to this research, as described in Chapter 7. Finally, the data from the interview and audio diary studies have been examined within the theoretical context of two different information models in Chapter 8. Adopting such an approach has helped to enhance our confidence in the subsequent findings by ensuring that the research is less vulnerable to errors and limitations linked to a particular method (Denzin, 1970; Patton, 2002).

3.7 Research Trustworthiness

The terms 'validity', referring to the extent to which the findings are accurate, and 'reliability', referring to the extent to which the findings are consistent (Nolan and Beni, 1995), are generally associated with the positivist paradigm and quantitative research (Winter, 2000). However, such notions are still important in qualitative research, although researchers have adopted alternative terms, such as 'trustworthiness', 'worthy', 'relevant', 'plausible', 'confirmable', or 'credible' (Hammersley, 1987; Guba and Lincoln, 1989; Mishler, 1990; Wolcott, 1990; Denzin and Lincoln, 1998).

A well-used and well-regarded (*e.g.*, Gerrish and Lacey, 2006) framework for assessing the trustworthiness of research has been used throughout this thesis; that of Lincoln and Guba (1985). This framework asserts that four key areas need to be considered when undertaking qualitative research. These are:

1. Credibility, *i.e.*, are the findings believable?
2. Transferability, *i.e.*, are the findings applicable elsewhere in similar groups/ situations?
3. Dependability, *i.e.*, if the study were repeated, would the same findings emerge?
4. Confirmability, *i.e.*, has the researcher biased the findings?

In practical terms (Fox *et al.*, 2001; Lacey and Luff, 2001), this means that throughout this thesis the precise parameters of the study have been clearly stated (who was studied, where and when, and by what methods); attempts have been made to ensure that the methods used are reproducible and consistent; and that the approach to and procedures

for data analysis have been clearly described and justified. In addition, the process of generating themes has been clearly documented. Ideally, the analysis should be undertaken by more than one person. Although this has not been possible here due to the research being undertaken as part of a Ph.D., the interpretation of the findings has been shared and discussed with the visually impaired advisors to this research. Care has been taken to ensure that the presentation of the findings is truly representative of the views expressed and that quotations are used from a wide range of participants. As described in Section 3.6, data have been gathered from more than one source in order to gain a fuller perspective of the situation. The initial findings have also been fed back to participants for checking and verification ("member checking"); and that reference has been made to the external evidence, including previous qualitative and quantitative studies, to test the conclusions from the analysis. Finally, the researcher has attempted to acknowledge the importance of reflexivity and to recognise that her social identity and background may have impacted on the research process (Gerrish and Lacey, 2006).

3.8 Ethics and Research Governance

The research presented here has been undertaken in accordance with the *Research Governance Framework for Health and Social Care* (Department of Health, 2005). This framework is designed to improve research and safeguard the public by enhancing ethical awareness and scientific quality; promoting good practice; reducing adverse incidents and ensuring lessons are learned; and forestalling poor performance and misconduct (Department of Health, 2005). Formal ethics committee approval, either from a local NHS Research Ethics Committee or the University's Faculty Ethics Committee, and/or NHS or social care research governance approval has, therefore, been obtained prior to each of the studies being undertaken. Further details are provided in subsequent chapters.

3.9 Public Involvement in Research

As noted at the start of this chapter, public involvement in research is an underlying principle of this thesis and such an approach has inevitably impacted on the methodologies used. This section, therefore, considers in detail the theory of public involvement, and how this has been applied to this research.

3.9.1 An overview of the literature relating to public involvement in research

UK policy now recommends that service users (patients, carers and the public) should be involved in all publicly funded health and social care research (Smith *et al.*, 2008). National Government publications, such as *Patient and Public Involvement in the New NHS* (Department of Health, 1999c), *Shifting the Balance of Power* (Department of Health, 2002a), as well as the *Health and Social Care Act 2001* (House of Commons, 2000), all advocate the importance of involving patients, carers and others in health and social care (Consumers in NHS Research, 2002a). The NHS Research and Development Strategy is committed to actively involving the public in the research process, rather than simply using them as “subjects” of research (Hanley *et al.*, 2004). The recent interest in public involvement is illustrated by the number of articles and editorials published in the *British Medical Journal* since the mid-1990s (*e.g.*, Chalmers, 1995; Oliver, 1995; Entwistle *et al.*, 1998; Crawford *et al.*, 2002; Simpson and House, 2002; Hanley *et al.*, 2004).

‘INVOLVE’ (formerly ‘Consumers in NHS Research’), a national advisory group to the Department of Health, was set up by the NHS Executive in 1996 to provide advice on how to achieve the involvement of patients and service users in all stages of the research process, including the prioritisation, commissioning, undertaking and dissemination of research (Hanley *et al.*, 2004). INVOLVE has also published numerous reports, including specific documents to aid researchers (*e.g.*, *Involving the Public in NHS, Public Health, and Social Care Research: Briefing Notes for Researchers* – Hanley *et al.*, 2004) and members of the public (*e.g.*, *The Public Information Pack* – Buckland *et al.*, 2007). More recently, the Social Care Institute for Excellence (SCIE) have produced several practice guides, resource guides and knowledge reviews on user participation (SCIE 2007a, 2007b, 2007c, 2007d). Much of the material contained in subsequent sections of this chapter is based on information extracted from these guides.

3.9.2 Definitions of public involvement

Various terms and definitions are used for ‘public involvement’; these include ‘user’, ‘service user’, ‘consumer’, ‘patient’, ‘client’, ‘lay person’, ‘advocate’, ‘citizen’, and ‘public’ (Herxheimer and Goodare, 1999; Boote *et al.*, 2002). In its broadest sense, a user or consumer can be thought of as a receiver, or potential receiver of health or social care (Boote *et al.*, 2002). This, therefore, includes carers and organisations that represent the

interests of people who use health and social care services, as well as patients and service users themselves (Hanley *et al.*, 2004). Various attempts have been made to classify users; for example, Boote *et al.* (2002) presented the three major types of consumers (individuals, local groups and (inter)national organisational consumer organisations) diagrammatically, as shown in Figure 2.

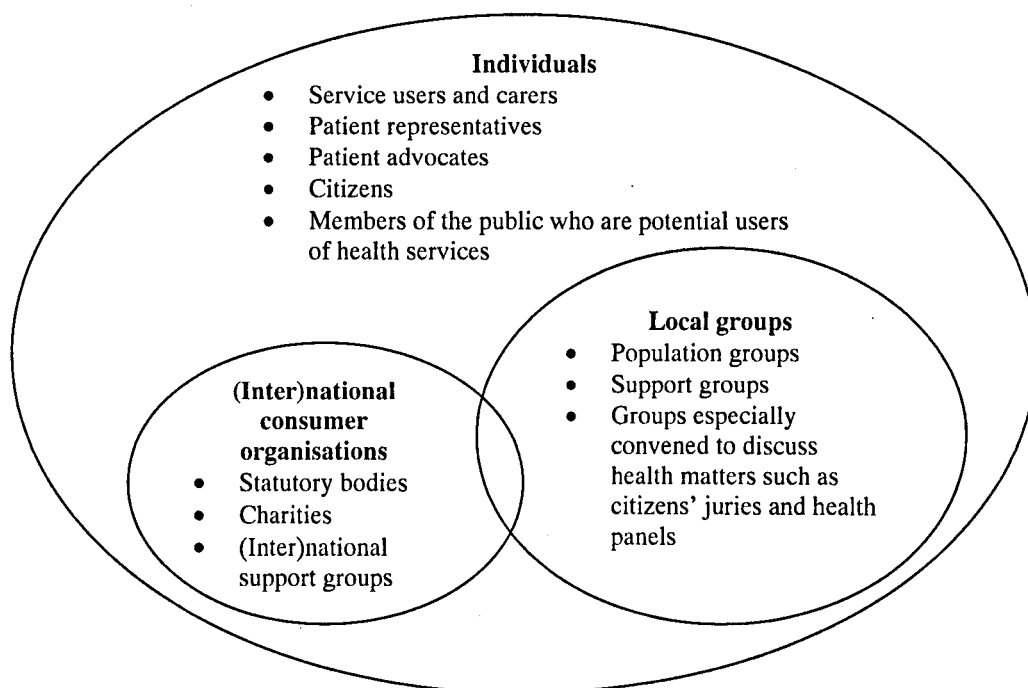


Figure 2. Classification of the public in relation to health care (reproduced with permission from Boote *et al.*, 2002: 217).

There is no single accepted preferred term (Telford *et al.*, 2002; Beresford, 2007), however; for example, 'user' has connotations with 'drug user' and substance misuse, while 'consumer' is often used in the business sector and, therefore, conjures up images of shoppers, market forces, *etc.* (Bastian, 1998). This is illustrated by the lack of consensus among a group of health professionals in a recent scoping study examining the extent of consumer involvement in research in one NHS region in England (Telford *et al.*, 2002). As Boote *et al.* (2002) note in a comprehensive review of the literature, it is interesting that,

"... in earlier definitions, consumers were defined negatively by reference to some other; those without either professional expertise or some kind of

vested interest. Later definitions have tended to be more positive, defining consumers in terms of who they are, not who they are not.” (Boote et al., 2002: 215).

There has been a noticeable shift in the terminology and approach used over recent years; for example, in 2002 at the start of this research, ‘consumer’ was the preferred term; this was superseded by ‘user’; and now the favoured term seems to be ‘the public’ (e.g., House of Commons Health Committee, 2007). This is illustrated by the changing of the name of ‘Consumers in NHS Research’ to ‘INVOLVE’. Forster and Gabe (2008) identified three distinct phases of patient and public involvement in England under the New Labour Government. The first phase was pre-2000 where the emphasis was on developing more easily accessible and qualitatively better patient information, such as via NHS Direct (Forster and Gabe, 2008). The second phase concerned the implementation of the *NHS Plan* (Department of Health, 2000) and focused on “empowering” patients and service users; for example, through the creation of Patient and Public Involvement (PPI) Forums. Finally, the third phase related to the publication of the *NHS Improvement Plan 2004* (Department of Health, 2004b) and the shift towards patient choice.

‘Public involvement’ is used to refer to an active partnership between the public and researchers in the research process, rather than the use of the public as the ‘subjects’ of research (Hanley *et al.*, 2004). Public involvement in research can be thought of as doing research *with* the public rather than *to, about, or for* the public (Hanley *et al.*, 2004).

3.9.3 Reasons for involving the public

Recent interest in public involvement appears to stem from policy directions (Boote *et al.*, 2002), in particular the Department of Health initiatives outlined in Section 3.9.1. Implicit in much of the literature, however, are two distinct discourses arguing in favour of public involvement in research (Boote *et al.*, 2002). The first is based on moralistic arguments, *i.e.*, it is ethically right for the public to have a voice in research which may ultimately impact on their health and social care status. The second is based on value statements and assertions as to how the public can have a positive impact on health research, *i.e.*, they are concerned with the benefits to the research process rather than to the public themselves. Both stances are valid. However it is important that both the researcher and user are clear about the benefits of public involvement (Hanley *et al.*, 2004). Several

studies (*e.g.*, Rhodes *et al.*, 2002) have alluded to these from the user's perspective, such as the ability to influence the research agenda and ensure that future research is appropriately prioritised and relevant to patients (Hanley *et al.*, 2004).

Public involvement also benefits the researcher and the research study itself. Authors have indicated that involving the public results in research that is more relevant, reliable and likely to be used (Chalmers, 1995; NHS Executive, 1999). Involving the public also helps to ensure that resources are not wasted on irrelevant research, people from marginalised groups are not excluded, and the findings of the results are appropriately disseminated and acted upon.

3.9.4 Levels of public involvement

There are several models of user participation (SCIE, 2007d), including Arnstein's ladder (Arnstein, 1969), Hart's ladder (Hart, 1992) and Treseder's circular model (Treseder, 2004). Arnstein's ladder of participation, for example, has rungs on the ladder representing increasing degrees of participation, ranging from non-participation or manipulation and therapy, through the tokenism of informing, consulting and placating; to citizen power through partnership, delegated power and user control (Oliver *et al.*, 2008). However, these have been developed in the context of more general community engagement and/or specifically in relation to children's participation in service planning. The only model which has been developed specifically in relation to research condenses Arnstein's ladder of participation (Oliver *et al.*, 2008) into three steps: consultation, collaboration and user-led (Hanley *et al.*, 2004).

Consultation is the simplest form of involvement, whereby users are simply consulted about the research (*e.g.*, at a one-off meeting). Collaboration involves an active, ongoing partnership between researchers and users in the research process. For example, users might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project. Finally, user-controlled (or user-led or emancipatory) research refers to research where users design, undertake and disseminate the results of a research project. User-led research requires the researcher to hand over the ownership of the project entirely to the user(s). This can be very difficult and, in some cases, it is not appropriate; for example, if

the research is being undertaken in order to obtain an academic qualification, as is the case for this research, where the researcher is expected to undertake the data collection and analysis themselves.

This categorisation of involvement, although a useful starting point, fails, however, to take into account some of the complexities associated with research. For example, the level of involvement will ultimately depend on the researchers, the users, the research methods, the time scale for the project, the resources available, *etc.* (Hanley *et al.*, 2004). There is also considerable overlap between the categories, particularly between consultation and collaboration (Boote *et al.*, 2002). Where possible, users should be asked at the start of the research how and when they would like to be involved (Hanley *et al.*, 2004).

3.9.5 Challenges to involving the public in research

A number of challenges must be overcome in order for the public to be effectively involved in a research study (Hanley *et al.*, 2004). These relate to the identification of suitable users, the resource and training implications of involving users and the ethics of doing so. There are also additional resource implications of involving users; these range from finding a suitable venue to paying users for their time and expertise (Hanley *et al.*, 2004).

Opponents to public involvement raise the issue of representativeness, *i.e.*, that it is impossible to identify users that represent a broad spectrum of opinions (Beresford and Campbell, 1994; Kelson, 1997). Supporters of user involvement argue that true representativeness is not possible for any research study. Instead attempts should be made to maximise diversity, as well as minimise bias.

There are also a number of financial implications of involving the public in a research study. INVOLVE and the Department of Health recommend in principle that all expenses (travel, accommodation, subsistence, childcare costs, carer costs, incurred by users should be reimbursed), while payments for time and expertise (to a level consistent with other members of the research team) should also be considered as best practice (Department of Health, 2006c; INVOLVE, 2006). There are several benefits to paying users: for example, it can be used as an added incentive to participation, a broader range of people can be involved because financial barriers are removed; it provides a tangible way of acknowledging the value of the user contributions; it supports the equity of power in

the research partnership between the user and the researcher; and it can be used to clarify the expectations and responsibilities relating to users' involvement (INVOLVE, 2006). It is important to be clear from the outset what payment the user can expect and when. Individual preferences for payment should also be taken into consideration; for example, some people may prefer not to be paid due to altruism, financial circumstances, or because social security benefits may be involved, whilst other people may prefer for a donation to be made to a relevant charity (INVOLVE, 2006).

3.9.6 Evaluations of public involvement in research

As SCIE (2007d) notes, "*whilst the service user participation movement has achieved much in terms of principle, it is less clear what changes have resulted in practice*" (SCIE, 2007d: 1). Similarly, Nilsen *et al.* (2006) concluded that, "*the effects of involving consumers in developing healthcare policy and research, clinical practice guidelines and patient information material remain largely unevaluated*" (Nilsen *et al.*, 2006: 10).

Systematic evaluations of the effects of involving the public in service development (*e.g.*, Crawford *et al.*, 2002; Rose *et al.*, 2002; Simpson and House, 2002; Daykin *et al.*, 2007; Fudge *et al.*, 2008) and research (Macaulay *et al.*, 1999; Oliver *et al.*, 2001; Boote *et al.*, 2002; Oliver *et al.*, 2004; Barnard *et al.*, 2005; Minogue *et al.*, 2005; Ross *et al.*, 2005; Boote *et al.*, 2006) have, however, started to emerge in the literature.

A qualitative systematic review, for example, found evidence that involving patients contributed to changes in the provision of health services (Crawford *et al.*, 2002). However, no evidence was found for the effects on use of services, quality of care, satisfaction, or health of patients (Crawford *et al.*, 2002). Consensus on eight principles and their related indicators of successful consumer involvement in the NHS was recently obtained (Telford *et al.*, 2004; Boote *et al.*, 2006). In an evaluation of the impact of consumer involvement in eleven research projects, Barnard *et al.* (2005) found that 82% of respondents agreed or strongly agreed that service user/ carer involvement had been useful and they believed that this kind of involvement in their project had had, or would have, a positive effect on outcome. In particular service user/ carer involvement had resulted in changes being made to the research questions and the questionnaires and interview schedules. In addition, service users'/ carers' explanations of the data related directly to how people experienced the delivery of services and they used their own

networks to tell other people about the research findings. However, little is still known about which approaches work best in different research contexts and why (Smith *et al.*, 2008). Smith *et al.* (2008) in their review of the research 'evidence' and current practice on service user involvement in the design and undertaking of nursing, midwifery and health visiting research concluded that it was not possible to state that involving service users will, or should, always be undertaken in the same way to achieve the same benefits.

3.9.7 Involvement of visually impaired people in research

There are a few examples in the literature of visually impaired people being encouraged to be involved in health and social care; the majority of these relate to service developments in response to policy and guidance documents, rather than research. For example, the *National Standards for Social Services for Visually Impaired People* (ADSS, 2002) recommend that consultation should take place on a regular and ongoing basis with people with visual impairments. Meanwhile, Willis *et al.* (2005) call for a user-led understanding of the outcomes for people with a visual impairment to be developed into strategic health and social care policies and practice. Practical advice (*e.g.*, CCNAP, 2001; Lewis, 2004; Ross *et al.*, 2005) on how to engage people with sensory impairments and older people in shaping health and social care services and research also now exists. Issues to consider include meeting the guiding needs of people, ensuring that the lighting is appropriate, and providing information in the person's preferred format.

Duckett and Pratt (2001) recently investigated the opinions of visually impaired people on visual impairment research. Participants suggested five main areas of concern for how research should be conducted: recruitment of participants, accessibility of research findings, power dynamics of research relationships, recognising the individuality of participants, and practicality and utility of research for visually impaired people (Duckett and Pratt, 2001). Participants felt that people with visual impairments should be consulted more thoroughly on research design and practice, and have more control over research activities (Duckett and Pratt, 2001).

Issues related to user involvement emerged as one of the main themes from the analysis of data obtained from interviews and focus groups with visually impaired people in Enfield, London (Papadopoulos and Scanlon, 2002a). The authors of this study concluded that

visually impaired people wanted to be involved in making decisions regarding the services they receive from health and social welfare services (Papadopoulos and Scanlon, 2002a).

Although several examples of research informed by an empowering and emancipatory paradigm are evident in the literature (Consumers in NHS Research, 2001), Duckett and Pratt (2001) were unable to find any such examples involving people with a visual impairment. However, a few examples have emerged recently, particularly within the "grey literature". In terms of visually impaired people's direct involvement in research, perhaps the most relevant example is a research project called '*Losing Sight in Ryedale*' which was undertaken by a group of people with serious sight loss in North Yorkshire (Crookes *et al.*, 1999). The first phase of the research (semi-structured interviews with people with visual impairments) was undertaken and analysed by a blind woman (Consumers in NHS Research, 2001). Another example of a user-led research project was conducted by Living Options Devon and looked at service provision after the diagnosis of permanent sight loss (Beer *et al.*, 2002). In the Beer *et al.* (2002) study, visually impaired users were involved in the design, production and execution of the research. Finally, the Cochrane Eyes and Vision Group now encourage visually impaired people to be involved in the systematic review process (Brodney-Folse *et al.*, 2003).

3.9.8 Limitations of existing research

It is clear that, although much has been published about the value of involving the public in research, very little objective evidence has been published to support this activity. Numerous small-scale studies offer anecdotal support to the process, however, in particular public involvement is said to result in research that is more relevant, reliable and likely to be used. In addition, despite the increasing number of examples in the disability literature of involving disabled people in participatory research studies, only a handful of studies have explicitly involved people with visual impairments. The research described in this thesis, therefore, attempts to address this knowledge gap by involving visually impaired people in the design and interpretation of three research studies. The impact of their involvement on the design and outcomes of this research are subsequently evaluated in Chapter 7.

3.9.9 Approach adopted for this research

As noted in Section 2.3.1, this research is based on a combined social and medical model of disability, similar to that adopted by the ICFDH (World Health Organisation, 2001a). This model was suitable for investigating the health and social care information needs of people with a visual impairment because it took into account the medical and social perspectives from the visually impaired and non-visually impaired perspective. Although many authors advocate the use of participatory action research methods for involving users in research, this is in conflict with traditional academic research paradigms. A compromise between these two stances was, therefore, adopted which sought to overcome the drawbacks of the traditional research approach, such as power issues involved in the researcher-participant relationship, but which also remained academically rigorous.

One of the major reasons for involving users in this research study was due to the researcher not having a visual impairment herself and was, therefore, reliant on people with a visual impairment to challenge her own assumptions about visual impairment; to ensure that important issues were not overlooked; and that the research was relevant and conducted in an appropriate manner. It was also hoped that the users would be able to help in the recruitment of participants and assist in the dissemination and implementation of the research findings.

A mixed consultative and collaborative approach to user involvement was adopted. It was not appropriate to undertake a user-led study, as explained in Section 3.9.4, because of the restrictions of undertaking an academic qualification. In terms of consultation, three local visual impairment support groups were consulted at the start of the research. In terms of collaboration, five visually impaired people were enlisted as advisors throughout the duration of the research study. Attempts were made to evaluate the involvement of visually impaired people in this research, which is an important and novel feature of this thesis. Further details about the process of involving visually impaired people in this research are provided in Chapter 7.

3.10 Conclusions

To conclude, this research has been conducted within a constructivist research paradigm and is based on a combined social and medical model of disability. The methodologies and methods employed have been chosen in response to the existing literature and good practice of involving people with a visual impairment in research, both as “subjects” and active contributors. The next four chapters go on to describe in more detail the methods and findings of the different studies making up this thesis: an interview study with two groups of visually impaired people (Chapter 4); an audio diary study with a small sample of older visually impaired people (Chapter 5); a survey of managers of local societies for the blind and partially sighted (Chapter 6); and an evaluation of the involvement of visually impaired people in the design of this research (Chapter 7). Chapter 8 triangulates and discusses the findings across all of these studies.

CHAPTER 4. INTERVIEW STUDY

4.1 Introduction

The existing literature, presented in Chapter 2, clearly identified the need for further research relating to the health and social care information needs and behaviour of people with visual impairments. Previous research studies have generally made the assumption that visually impaired people are a homogenous group of people that simply require the same health and social care information as totally sighted people but that this information should be provided in alternative formats. The importance of other aspects of health and social care information, such as the content, quality, timing, sources and support mechanisms available, has largely been ignored. The first phase of this research was, therefore, designed to explore in detail the health and social care information needs of two groups of visually impaired people: people who had an age-related visual impairment, and people who had a visual impairment since birth or early childhood. This research builds on the methodological literature reviewed in Chapter 3 by adopting one of the most appropriate methods (qualitative interviews) for studying the information needs of visually impaired people. This chapter, therefore, describes in detail the methods used for this study (Section 4.3), presents the major interview findings and discusses these in the context of the existing literature (Section 4.4), and then concludes by identifying key implications for practice and future research (Section 4.5).

4.2 Aim and Research Questions

The aim of this study was to explore in-depth the health and social care information behaviours of people with a visual impairment. In particular, the study aimed to provide answers to the following research questions:

1. What are the major health and social care information needs of people with a visual impairment?
2. What information sources do people with a visual impairment use to obtain information about health and social care matters?

3. What factors (*e.g.*, type of visual impairment, length of diagnosis, *etc.*) affect the health and social care information behaviour of people with a visual impairment?
4. To what extent can current developments in information provision (*e.g.*, NHS Direct and the Internet) help to meet the health and social care information needs of people with a visual impairment?
5. Can two established information models (Wilson, 1999 and Moore, 2002) explain the information behaviour of visually impaired people seeking health and social care information?

While questions 1 to 4 are addressed in this chapter, the final question is discussed in detail in Chapter 8, alongside all the findings of the studies undertaken as part of this thesis.

4.3 Methods

4.3.1 Study design

Chapter 3 introduced the constructivist paradigm (Patton, 2002) within which the research discussed in this thesis was conducted. This first phase of the research was exploratory and, therefore, qualitative in nature. It comprised individual semi-structured face-to-face and telephone interviews with people with a visual impairment.

A qualitative approach was most appropriate because the area was under-researched and the methods employed allowed the researcher to explore issues in greater depth than would have been possible with quantitative methods. The methods were also in line with the constructivist paradigm and, as discussed in Section 3.3, most authors (*e.g.*, Wilson, 1981) advocate the use of qualitative research methods to undertake studies of information behaviour.

The researcher had originally planned to undertake focus groups with people with a visual impairment; however, the results of a review of the literature and a consultation exercise with people with a visual impairment, as discussed in Chapter 7, revealed that individual face-to-face interviews were a more appropriate research method. People's information needs were likely to vary between individuals and conducting interviews in a group

situation could result in certain views being overlooked. In addition, people involved in the consultation exercises thought that they would feel more at ease and less inhibited being interviewed individually.

4.3.2 Sampling and recruitment

In order to test the assumption that visually impaired people were a single homogeneous group, two groups of people were recruited for this interview study: people who had experienced sight loss later in life due to age-related causes (Group A) and people who had been diagnosed with a visual impairment at birth or during early childhood, (Group B). It was envisaged that this former group would primarily comprise people with the same or similar diagnosis (*e.g.*, age-related macular degeneration, AMD). This approach was chosen because it allowed an in-depth comparison of the information behaviour of two groups of people with different visual impairments. It was decided that a sufficient number of interviews would be undertaken with both groups of people in order to reach a point of data saturation (referred to as the “point of redundancy” by Lincoln and Guba, 1985) within both groups. Based on previous research (*e.g.*, Duckett and Pratt, 2001), it was thought that this was likely to occur after 10-15 interviews with people from each group, *i.e.*, 20-30 interviews in total.

A purposeful (or judgment) method of sampling (Patton, 2002) was used. Although qualitative research does not aim to be generalisable, a range of people were interviewed in order to increase the transferability of the findings. Both men and women, from a variety of age groups and different socio-economic groups, as well as people who lived alone and those who lived with family and/or friends were, therefore, interviewed.

A variety of recruitment methods were utilised, including:

1. Placing an advert in the local society for the blind newsletter which was produced in a variety of formats (*e.g.*, large print, audio tape, Braille, *etc.*) and which was circulated to both registered and non-registered people with a visual impairment across the local area.
2. Advertising in the local Talking News, a weekly digest of local news items provided on audio tape to both registered and non-registered people with a visual impairment across the local area.

3. Contacting local visual impairment support groups, such as the local Macular Disease Society support group.
4. Following up recommendations from the advisors to this research study.
5. Following up referrals from the local society for the blind and partially sighted.
6. Using the recruitment approach adopted for the audio diary study (*i.e.*, via the Low Vision Clinic at the local hospital), as discussed in Chapter 5.

4.3.3 Procedure and materials

Once a person had agreed to take part, they were contacted by the researcher to arrange a semi-structured interview. The participants were given the choice of the type (face-to-face or telephone) and venue for the interview (in their own home, at the University, or at a neutral venue, such as the local society for the blind). At this point, the participants were sent an information sheet in their preferred format (*i.e.*, large print, audio tape or email) outlining the study in more detail (refer to Appendix C). Due to resource constraints and the small number of people to whom this would apply, the information sheet was not provided in Braille or Moon. Before the start of the interview, participants were asked to consent verbally to take part in the study. Verbal consent was chosen for this study because this more accessible to the participants than traditional written consent.

The first interviews were structured using a detailed interview schedule; however, as the researcher became more familiar and confident with the process, a more semi-structured approach was adopted, using the topic guide provided in Appendix D. The topic guide was piloted with two of the advisors to the research study, one of whom had an age-related visual impairment and one who had had a visual impairment since being a child. The interviews covered the information that 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 given an opportunity to suggest ways in which the existing provision of health and social care information could be improved for people with a visual impairment. In addition, background demographic data about each participant were collected. The interviews were tape-recorded using a *Sanyo Talk-Book VAS Compact Cassette Recorder TRC-1148*, with permission from the interviewee.

4.3.4 Analysis

Within four weeks of each interview, the tape recorded interview data were transcribed verbatim into *Microsoft® Word 2002*. The demographic data collected for each participant were entered into the *Statistical Package for the Social Sciences (SPSS)* version 11.0.1. The relatively small sample sizes involved (28 interviews and 31 interviewees) meant that only descriptive statistics were used, to describe the characteristics of the sample (Cohen, 1992). The socio-economic status of the participants was determined according to the *National Statistics Socio-Economic Classification (NS-SEC)* (National Statistics, 2003). This classification has eight classes which range from 'Higher managerial and professional occupations' to 'Never worked and long-term unemployed'.

The transcripts were analysed using framework analysis (Ritchie and Spencer, 1994) and followed the five stages outlined in Section 3.5.1. Initially all the interviews were read carefully so that the researcher became familiar with the data and acquired an overview of the richness, depth and diversity of the data. An initial thematic framework was developed based on the interview topic guide and familiarisation with the interview data. This framework was tested and modified in response to a detailed analysis of two interviews covering both interview groups. In response to this exercise, it was decided that it was appropriate to develop a single index across the two interview groups, but for any differences to be highlighted. Ritchie and Spencer (1994) advocated flagging up themes within the margins of individual transcripts; however, an alternative approach was used which involved electronically copying and pasting across quotations from the individual transcripts into a single *Microsoft® Word 2002* document organised according to the thematic framework. Quotations elicited from interviews with people with a visual impairment since birth or early childhood were recorded in a different colour font (blue) to facilitate identification of similarities and differences between the two interview groups.

This procedure was repeated until half the interviews (n=14) had been analysed. This sample included eight interviews with people with an age-related visual impairment and six interviews with people with a visual impairment since birth or early childhood, *i.e.*, proportional to the total number of people interviewed in each group. Although minor changes were made to the framework during this time, a major revision of the framework was undertaken at this half-way stage. This was because the researcher became more familiar with the data and acquired a different perspective on the research findings. The

remaining interviews were subsequently analysed and minor modifications made to the thematic framework. Once all the interviews had been analysed, the thematic framework was revisited again. The frameworks indicated that the point of data saturation (*i.e.*, when no further themes were identified) was reached after 24 interviews. Thematic charts were subsequently developed for each of the major themes. This helped to identify patterns, associations, concepts and explanations in the data (Ritchie and Spencer, 1994). To underpin the theoretical basis of this research, the findings were analysed in the context of two information models (Wilson, 1999; Moore, 2002); this analysis is presented in Chapter 8.

4.3.5 Trustworthiness

As noted in Chapter 3, Lincoln and Guba's (1985) model for assessing the validity of qualitative research was used. In terms of credibility, the precise parameters of the study were clearly documented, *i.e.*, with regard to the population (visually impaired people) investigated, the sampling method, the methodology employed, *etc.* A reliable (*i.e.*, in terms of dependability and confirmability) means of measurement (a semi-structured interview topic guide) was also used. The topic guide was piloted with two of the advisors to the study. A sampling method was adopted that aimed to maximise the diversity of visually impaired people within the study setting to ensure that a 'rich' picture could be cleaned. Finally, to minimise intra-observer reliability and increase confirmability prolonged contact with the participants was established. This included sending all participants large print, embossed thank you and Christmas cards, as well as distributing a summary of the interview study findings to participants in their preferred format. The researcher subsequently telephoned a random sample of participants to establish whether the results accurately represented their views.

4.3.6 Ethical approval

The interview study was approved by the Department of Information Studies Research Committee and followed the University of Sheffield Research Ethics Policy. Since the study recruited participants via a voluntary agency and was undertaken prior to April 2004, formal NHS Local Research Ethics Committee (LREC) was not required. However, principles of good ethical practice (*e.g.*, provision of information sheet, obtaining of

informed consent, anonymisation of data, confidential storage of data, etc.) were adhered to.

4.4 Findings

4.4.1 Response rate

Twenty-nine interviews were conducted in total between the 30th September 2003 and the 2nd March 2004. This equated to 32 people because three visually impaired couples were interviewed. 16 of the interviews (17 people) were conducted with people with an age-related visual impairment, while 12 interviews (14 people) were conducted with people with a visual impairment since birth or early childhood. Finally, 1 interview (1 person) was conducted with a person who did not fit into either of these two categories. It emerged during the interview that this person had a very rare eye condition, Leber's optic neuropathy, which is typified by sudden onset in adulthood. This person, therefore, did not meet the inclusion criteria for this study, and was excluded from the formal analysis. However, the interview was completed because the participant clearly still wanted to tell his story. Two of the people interviewed also took part in the audio diary study, as described in Chapter 5.

4.4.2 Format of the interviews

In total, 23 interviewees (16 with an age-related visual impairment, and 7 with a visual impairment since birth or early childhood) chose to have a face-to-face interview in their own home, 1 interviewee (with an age-related visual impairment) opted for a face-to-face interview at the University, while 7 expressed a preference for a telephone interview. All of the people opting for a telephone interview had a visual impairment since birth or early childhood.

4.4.3 Duration of the interviews

Across all the interviews, the mean interview duration was 46 minutes (median: 40 minutes, range: 18-131 minutes; N=28). In terms of the transcription length, this corresponded to a mean word count of 5,347 words (median: 4,140 words, range: 1,391-18,879 words; N=28). For the interviews with people with an age-related visual

impairment, the mean interview length was 51 minutes (median: 44 minutes, range: 22-131 minutes; N=16) which corresponded to a mean of 5,640 words (median: 4,681 words, range: 1,391-18,879 words; N=16). The mean interview length for people with a visual impairment since birth or early childhood was lower at 39 minutes (median: 29 minutes, range: 18-91 minutes; N=12) which corresponded to a mean of 4,958 words (median: 3,497 words, range: 1,660-13,721 words; N=12).

4.4.4 Demographic characteristics of interviewees

Table 1 presents the major demographic characteristics of the interview participants. These are described in more detail below, but, to summarise, a range of people, both male and female, from a variety of age groups and different socio-economic groups, as well as people who lived alone and those who lived with family, were interviewed. This, therefore, suggests that the findings are potentially transferable (Lincoln and Guba, 1985) to other people with these types of visual impairments.

4.4.4.1 Age

The mean interviewee age was 62.42 years (range: 19-91 years; N=31). The mean age for the interviewees with an age-related visual impairment was higher, 80.24 years of age (range: 58-91 years; N=17), compared to 40.79 years of age (range: 19-77 years; N=14) for participants with a visual impairment since birth or early childhood. The majority (n=14) of participants with an age-related visual impairment were aged over 70 years. In contrast, the majority (n=12) of participants with a visual impairment since birth or early childhood were aged 60 years or younger. Nine of these interviewees were aged under 40 years.

Table 1. The major demographic characteristics of the interview participants. (A refers to people with an age-related visual impairment; B refers to people with a visual impairment since birth or early childhood. Percentages are not provided as these could be misleading given the relatively small sample size.)

	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
Living with other people			
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 status¹			
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
9. Occupations not stated or inadequately described	5	5	0

¹ Based on National Statistics (2003) *The National Statistics Socio-economic Classification (NS-SEC)*. London: National Statistics. Available: http://www.statistics.gov.uk/methods_quality/ns_sec/ [Accessed 07 November 2003].

4.4.4.2 Gender

In total, 15 men and 16 women were interviewed. However, this was not equally distributed across the two interview groups. Only 6 men (out of 17) were interviewed with an age-related visual impairment, whereas 9 men (out of 14) were interviewed with a visual impairment since birth or early childhood.

4.4.4.3 Ethnic origin

Thirty of the 31 interviewees were white-British. The remaining interviewee, who had had a visual impairment since birth, was Asian British – Pakistani.

4.4.4.4 Marital and living with others status

Twelve of the 31 interviewees were widowed; this proportion was higher in the age-related visual impairment group. Thirteen of the interviewees lived with their spouse; 12 lived alone; and four, all with a visual impairment since birth or early childhood, lived with their parent(s). Two interviewees, both with an age-related visual impairment, lived with their child(ren). A higher proportion of participants with an age-related visual impairment lived alone, compared to those with a visual impairment since birth or early childhood.

4.4.4.5 Employment status

Seventeen of the 31 interviewees were retired (16 of whom had an age-related visual impairment); 9 were unemployed; 3 were either employed or self-employed, all of whom had a visual impairment since birth or early childhood; and 2 were students, again both of whom had a visual impairment since birth or early childhood.

4.4.4.6 Socio-economic status

Ten of the 31 interviewees either had never worked or were long-term unemployed. Nine of these people had a visual impairment since birth or early childhood. Five of the interviewees (four of whom had an age-related visual impairment) had intermediate occupations, *i.e.*, positions not involving general planning or supervisory powers, in clerical, sales, service and intermediate technical occupations. Five of the interviewees (again four of whom had an age-related visual impairment) had routine occupations, *i.e.*,

positions where employees are engaged in routine occupations which had a basic labour contract.

4.4.4.7 Electoral ward

Participants originated from 15 of the 28 electoral wards in Sheffield, as shown in Table 2. In addition, two interviewees lived outside the city boundary in the Peak District. Eight of the wards where people were interviewed (equivalent to 18 participants) had a standardised health score of more than 100, indicating a higher than average level of deprivation (Sheffield City Council, 2004).

Table 2. Electoral ward of the interview participants (A refers to people with an age-related visual impairment; B refers to people with a visual impairment since birth or early childhood. Standardised health scores of more than 100 indicate a higher than average level of deprivation.)

Ward	Total (N=31)	A (N=17)	B (N=14)	Standardised health score ²
Manor	2	1	1	144.71
Southey	1	0	1	129.81
Shiregreen and Brightside	2	0	2	119.92
Richmond	2	1	1	109.58
Gleadless Valley	4	1	3	109.13
Woodhouse	1	1	0	103.96
Beauchief and Greenhill	4	2	2	103.04
Birley	2	1	1	100.63
Hillsborough	1	1	0	91.17
East Ecclesfield	1	0	1	89.20
Beighton	1	0	1	87.72
Nether Edge	2	2	0	80.87
Crookes	1	1	0	70.64
Dore and Totley	4	4	0	58.79
Fulwood	1	0	1	52.96
Other (Bamford)	2	2	0	Unknown

² Taken from Sheffield City Council (2004). *Sheffield's New Wards – A Census Profile*. Available: <http://www.sheffield.gov.uk/facts-figures/2001-census/newwards> [Accessed 18 May 2004].

4.4.5 Participant characteristics

Table 3 presents the characteristics of the participants in terms of their visual impairment.

Table 3 The characteristics of the interview participants in terms of their visual impairment (A refers to people with an age-related visual impairment; B refers to people with a visual impairment since birth or early childhood. Percentages are not provided as these could be misleading given the relatively small sample size.)

	Total (N = 31)	A (N = 17)	B (N = 14)
Type of visual impairment			
Age-related macular degeneration (AMD)	7	7	0
Age-related macular degeneration (AMD), 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

4.4.5.1 Type, length and registration of visual impairment

The type of visual impairment experienced by participants varied considerably between the two groups. The majority of interviewees with an age-related visual impairment had a diagnosis of AMD alone (n=7); AMD, plus cataracts (n=5), or glaucoma (n=2). Participants with a visual impairment since birth or early childhood exhibited a wider range of diagnoses; the most common being glaucoma (n=3) and cataracts (n=2), but also included congenital eye conditions, such as congenital macular dystrophy, retinitis pigmentosa, nystagmus; other congenital health conditions, such as albinism; and trauma resulting from a car accident.

The majority (n=28) of interviewees had had a visual impairment for more than 12 months. All of the interviewees with a visual impairment since birth or early childhood had had their impairment for more than 10 years.

Table 3 also shows that most of the interviewees (n=27) were registered as either blind or partially sighted. Just over half (n=18) of participants were registered as blind, while 9 were registered as partially sighted. Almost all (n=13) of the participants with a visual impairment since birth or early childhood were registered as blind, whereas the majority (n=8) of participants with an age-related visual impairment were registered as partially sighted. All of the participants with a visual impairment since birth or early childhood were registered as either blind or partially sighted, whereas three of the participants with an age-related visual impairment were not registered, either because they were not eligible to be (n=2), or because they were unaware of the registration process (n=1).

4.4.5.2 Presence of other health conditions

Over three quarters (n=24) of the participants experienced other health conditions, or comorbidities; this figure was higher amongst people with an age-related visual impairment. The types of additional health conditions differed between the two groups of interviewees: the most common conditions amongst participants with an age-related visual impairment were breathing difficulties (*e.g.*, asthma, emphysema) (n=4), arthritis (including mobility problems) (n=4), heart problems (*e.g.*, angina) (n=3), hearing impairment (n=3), osteoporosis (n=2), nervous problems (*e.g.*, neuropathy) (n=2), insulin-dependent diabetes (n=1), and other conditions (*e.g.*, scleroderma, diverticulitis, vibration white finger) (n=3).

The health conditions experienced by the participants with a visual impairment since birth or early childhood included arthritis and mobility problems (n=4), heart problems (n=2), asthma (n=2), gall stones (n=1), depression (n=1), epilepsy (n=1), and other conditions (e.g., eczema, migraines) (n=3).

4.4.6 Key interview themes

Four broad themes were identified in the final framework. These were:

- A. Health and social care information needs.
- B. Sources of health and social care information.
- C. Factors affecting information behavior.
- D. Improvements in the provision of health and social care information.

Each of these themes, and their related sub-themes, are presented visually and described in more detail below. Illustrative quotes are provided. These quotes are coded using a letter (A or B), a number (A1-A17 and B1-B14), and the line numbers from the corresponding transcript. 'A' refers to interviewees with an age-related visual impairment and 'B' refers to interviewees with a visual impairment since birth or early childhood.

Theme A. Health and social care information needs

From the interviews it was became apparent that participants raised a number of issues relating to their health and social care information needs, ranging from the type of information to how they accessed this information. These sub-themes are presented in Figure 3.

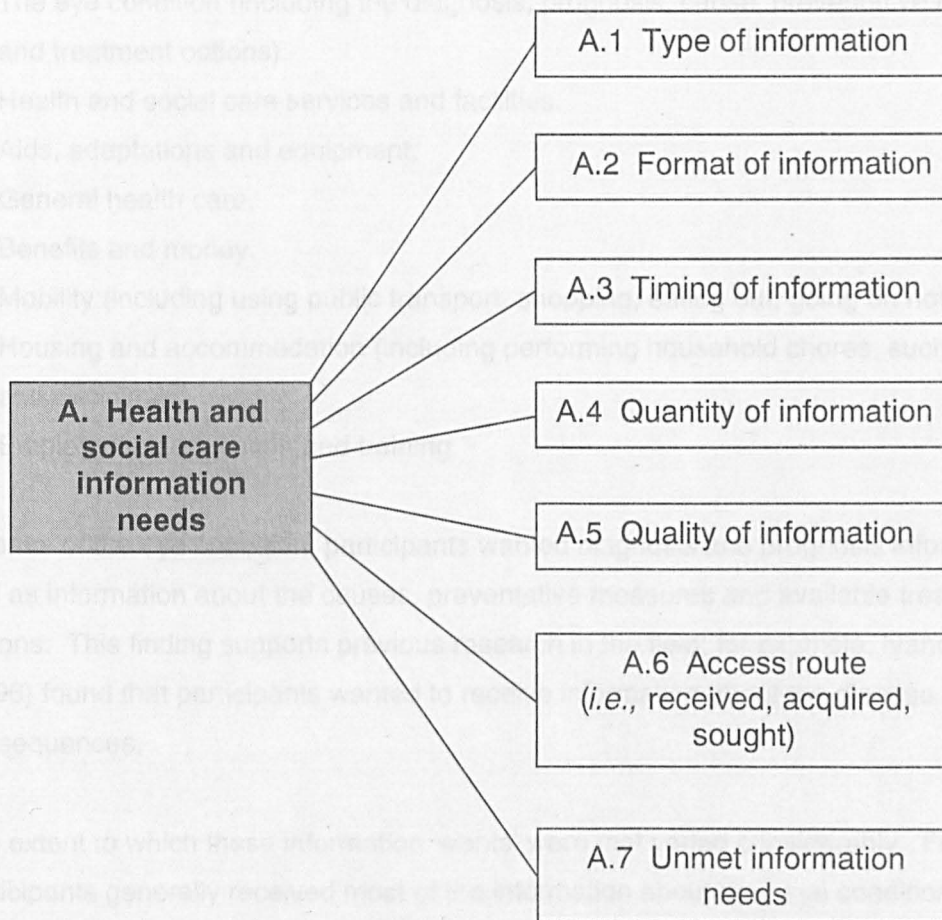


Figure 3. The interview sub-themes of Theme A 'Health and social care information needs'.

A.1 Type of information

Visually impaired participants in this interview study needed eight major types of information about health and social care matters. These were very similar, although not identical, to the categories identified by Moore (2000). The comparison with Moore's (2002) model of social information need is discussed in Section 8.3.1. For the purpose of this chapter, however, it is helpful to identify the following types of health and social care information:

1. The eye condition (including the diagnosis, prognosis, cause, preventative measures and treatment options).
2. Health and social care services and facilities.
3. Aids, adaptations and equipment.
4. General health care.
5. Benefits and money.
6. Mobility (including using public transport, shopping, eating out, going on holiday, etc.).
7. Housing and accommodation (including performing household chores, such as cooking and cleaning).
8. Employment, education and training.

In terms of the eye condition, participants wanted diagnosis and prognosis information, as well as information about the causes, preventative measures and available treatment options. This finding supports previous research in the field; for example, Ivanoff *et al.* (1996) found that participants wanted to receive information about the disease and its consequences.

The extent to which these information 'wants' were met varied considerably. For example, participants generally received most of the information about their eye condition at the same time as being diagnosed by the ophthalmologist, as illustrated by the following quote by a participant who was diagnosed with AMD:

"He says, 'You've got no sight in your left eye and a quarter left in your right eye ... and it will go and ... I honestly can't do anything for you, dear'. He said, 'It's a clot ... it's a macular ... and it's wet.' (A16, lines 20-22)

It emerged that a few participants actually started to self-diagnose themselves in response to the information they had acquired themselves, for example, via the media:

"... there was a big article in The Star about macular ... people complaining about ... going blind because of the cost of the treatment ... and ... I saw this thing about the blood vessels ... and I thought that's me ... that's what I've got ... nobody had explained it ..." (A13, lines 105-108)

Another participant with a visual impairment since early childhood recalled the information he had received about the prognosis of his eye condition:

"I was told it developed from the age of 8 ... and was expected to sort of level out by the age of 18 ... err ... which is pretty much what happened ..." (B6, lines 73-75)

However, other participants learnt more about the prognosis of their visual impairment through other people they knew:

"... I've known two people that have had it ... a sudden burst of things happening in their eyes ... blood vessels ... goes ... berserk ... they have treatment straight away ... and they're ok." (A13, lines 46-48)

In terms of information about treatment options for their eye condition, many participants were informed that there was currently no treatment available, as illustrated by the quotes below:

"Well, from what they told me ... they can't do much for me." (A8, line 211)

"... and ... err ... they tell me there is no cure for it as yet ..." (B7, lines 35-36)

For those participants where treatment options did exist, the ophthalmologist generally provided information about the advantages and disadvantages of the intervention and the overall success rates; for example:

"... and then told me exactly the pros and cons of laser treatment ... that it has a 50% chance of succeeding and a 50% chance of it not returning. So a 25% chance of it working overall." (A17, lines 157-159)

"... but they did go into details that they can't guarantee, your eyes might be worse ... and ... erm ... you might lose your sight altogether ... and ... err ... but, on the other hand, it might improve it, but ... if just for a short while." (A3, lines 150-153)

The decision about whether or not to go ahead was then left in the hands of the patient, as illustrated by the above participant's explanation:

"But I can remember thinking, 'Oh shut up, I'm going to have it'. [Laughs]. Because I felt that ... if there was a way ... even if it was only for 6 months ... that I could see things clearer again ... err ... to me ... it would be worth it ..." (A3, lines 154-157)

However, it was also evident in that some participants were given only a very short period of time in which to decide about whether or not to proceed with the treatment:

"Well, I mean I had to decide on the day whether to go ahead with it ..."
(A17, line 161)

Many participants learnt about the treatment options available for their eye condition from the media, as illustrated by the following quote:

"... and apparently somebody sent me some information about an operation they could do ... where they took your eye out and turned the macular round, then you could see better ... because part of the macular wears out evidently." (A7, lines 116-119)

It was also evident that several participants attempted to seek out additional information about their eye condition independently, particularly about the causes:

"Err ... it's only going through research that ... they've found out it's the connective gene ... and the characteristics of me ..." (B14, lines 25-26)

The majority of participants also wanted information about the health and social care services that were available to them. It emerged that many participants found out about different social care services, in particular mobility training and financial benefits, through friends, family members, support groups and talking newspapers, rather than through formal channels. This is illustrated by the following quote:

"the other thing ... I've not told you about ... was any of the help that was available through Social Services ... I've had to ask all the time ... and I've had to find out for myself." (A12, lines 365-367)

In addition, participants wanted information about aids, adaptations and equipment, such as visual aids (e.g., magnifiers), available from the hospital low vision clinic and local opticians, as well as white canes, talking books, talking watches, liquid level indicators and coin holders.

"... I go to the low vision clinic which I was told about ... and they give me a torch ... a torch magnifier ... which is very good ... but very exhausting ..."
(A1, lines 242-243)

"Oh a measuring thing I could put in a cup, so that when it reached a certain level it made a little peep. Various things, like that." (A3, lines 97-98)

In terms of general health information, participants wanted to know about the medications they were taking for other health conditions, such as possible side effects, as well as how to administer and identify medications, such as different tablets. It was evident that

participants used a number of innovative approaches to help them to administer medications, both for their visual impairment and for other health conditions. They generally acquired this information from friends, family and local support groups. For example:

"... I have some eye drops ... and I can tell the difference between the different makes because they are different shaped bottles ..." (B3, lines 106-107)

"The wife works out all the tablets and she gives 'em me in the morning ... you know?" (A4, lines 143-146)

"I've got a very good memory. I know which are the right ones ... by feeling the different packages ... and then the tablets themselves ... I know there are the little round ones ... and the larger ones ..." (B4, lines 80-82)

Although recent research by the University of Birmingham (2008) has helped to identify the optimum Braille dot height for use on pharmaceutical products, it is important to remember, however, that only an estimated 2% of the visually impaired population can read Braille (Gregory, 1996).

Participants also needed medical information, such as hospital letters and appointment cards, prescriptions, hospital notices and signs, etc., to be produced in an accessible format, as illustrated by the following quote:

"... 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, lines 15-16)

This was not always forthcoming, however, and participants had to rely on others to read this information for them:

"If a letter comes ... you have to ask a warden to open it up ... or wait 'til your daughter comes down." (B5, lines 320-321)

It also emerged that participants had specific information needs relating to the financial benefits they were entitled to, as illustrated by the following quote:

"... I lost a lot of benefits that I could have claimed ... had it been made known to the DHSS ... that I was registered blind. This only came to light when we went down to try and get some information." (A5, lines 58-60)

Recent research by Douglas *et al.* (2008) estimated that there were 10,000 people registered visually impaired who were currently not receiving Disability Living Allowance (DLA) and 73,000 people who were not receiving Attendance Allowance, even though they were eligible to apply. This study also found clear evidence that receiving information and advice about these benefits was associated with a successful application. This, therefore, indicates a need for information and support to be made more readily available to visually impaired people about the financial benefits available to them.

In terms of mobility, participants required a range of information in accessible formats. This included public transport and travel information, notices in shops, menus in restaurants, *etc.* Many of these information needs were unmet, as illustrated under Theme A.7.

Participants also had various information needs relating to housing and accommodation, including performing household chores, such as cooking and cleaning. Several participants encountered difficulties when preparing food and when cooking. It emerged that two people had heard about a device which helped to identify the contents of different tins:

"Dymotape. And we Braille things on the stripper tape ... and then put it onto the tin ..." (B8, lines 275-276)

It was, noted, however that this Braille labeller had its limitations:

"We have to abbreviate a lot of things ... 'cos ... Braille, being as cumbersome as it is, err ... it would overlap the tin lid ..." (B7, lines 277-278)

Finally, some participants, particularly those from Group B, had employment, education and training information needs. However, these were generally unmet needs, as discussed under Theme A.7.

These findings are in line with previous research in the field which has found that having a visual impairment affects various aspects of a person's lifestyle (National Statistics, 2001). In particular, as Bruce *et al.* (1991) found, the majority of visually impaired people experience difficulty with at least one area of daily living skills, such as personal care and domestic tasks. Despite the focus of this research being on the health and social care

information needs of people with a visual impairment, participants tended to focus on their social care information needs, in addition to their need for information about their eye condition. Although approximately three quarters of participants had one or more additional health conditions and/or disabilities, very few participants referred to their information needs relating to other aspects of their health care, apart from being unable to read medical correspondence and the difficulties they encountered when administering medications, such as tablets. 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. This may imply that participants' health information needs were already being well met and that, in the future, the emphasis should be on addressing visually impaired people's social care information needs, possibly by building upon participants' suggestions for service improvements, as described under Theme D below.

A.2 Format of information

The format of the information, regardless of the access route, was important to participants. It emerged that the majority of information received or acquired was verbal, as illustrated by the following quote:

"Oh no ... it was all given verbally." (A1, line 279)

However, it was also evident, particularly over recent years that, the information was also being provided in written form as well:

"I have all the leaflets ..." (A16, line 126)

Group A participants generally preferred information to be provided verbally, in large print, or on audio tape. The following participant, for example, described how much more accessible she would find information if it was sent on audio tape:

"A lot of information that you do get ... would be easier if you could get it on tape. I mean ... err ... I have things ... which if you could get it on tape ... it would be much easier ... because he could listen to it then." (A5, lines 627-629)

The majority of Group B participants commented on the importance of Braille. However, one person who, despite going to a partially sighted school, had never been taught Braille, and so he highlighted some of the limitations of providing information in this format:

"To start off with I don't know anybody else what's got Braille ... so what ... what good's Braille to me? I can't send it to anybody ...' I says, 'And I'm not likely to get any letters where I'm likely to need it'." (B5, line 681-683)

Another participant highlighted the additional difficulties facing people who had a dual sensory impairment:

"Err ... how do you tell a person who is severely deaf-blind anything ... you can't ..." (A12, lines 996-997)

Many participants expressed their frustration about the lack of provision of information in alternative formats, even by health and social care organisations. The following participant encountered particular problems with both Social Services and the local hospital who, despite knowing her preferred format for information (Braille), continued to provide information in large print for her, which she was unable to read:

"Err ... well ... I think the problem with that ... erm ... on a personal and professional use ... err ... it's been very unforthcoming really ... things into alternative ... what's the word I'm looking for? ... methods ... like Braille, large print ... erm ... for material. And ... erm ... there's ... erm ... the thing with ... the Social Services ... err ... not really ... erm ... I find it's a catch 22 situation, because ... erm ... things don't really get put ... and I think this is a national problem as well ... things don't tend to get put in alternative material ... because people don't really know what to ask for ... and people are never really told. Because when it all boils down ... it costs money." (B14, lines 113-121)

However, several participants did state that they thought the situation had improved in recent years, as illustrated by this quote from this Group A participant:

"Err ... it's much better now I think ..." (A12, line 213)

A.3 Timing of information

It emerged during the interviews that participants received the majority of information from the ophthalmologist immediately after their visual impairment had been diagnosed.

Despite having considerable information needs at this time, participants questioned the

appropriateness of receiving so much information at such a stressful time. The following quote demonstrates the shock that many participants, particularly those with an age-related visual impairment, felt upon receiving their diagnosis:

"The other thing is ... people are extremely concerned when they turn round to them and say, 'Sorry. We can't do anything for you'. Now ... really a shock. They've gone in hope ... and that's it ... nothing ..." (A15, lines 340-342)

"Many people going into the hospital are frightened and the consultants are frightening." (A12, lines 1181-1182)

Other participants found the period between diagnosis and treatment and the lack of information provided during this period difficult:

"... and that is a long gap ... between ... you know, the first ... erm ... becoming aware of the problem and starting treatment and erm ... going to the low vision unit ..." (A17, lines 137-140)

Interestingly, some participants could not remember what information they had actually received at the hospital. For example:

"I don't know ... I can't remember." (B2, line 56)

Other participants indicated that they simply did not want more information at the time of diagnosis:

"No, but then I'd had enough, so I wouldn't have listened." (A11, line 40)

Although this may be explained by the long period elapsed from the time of diagnosis for some participants, it may also indicate that the method of communication (predominantly verbal) was not always effective in the longer term. It also questions the appropriateness of providing so much information at the time of diagnosis. A more effective approach, therefore, might be to provide the information in stages over time.

These findings also suggest that people with visual impairments should be more engaged in the process and should help to identify when it would be most beneficial to receive different types of information. For example, although some participants valued receiving a lot of information at the time of diagnosis, others found this overwhelming. Two studies by Donnelly (1997a, 1997b) specifically examined the information needs of visually impaired

people at, or shortly after, the time of diagnosis. Both these studies stressed the importance of information and/or advice being available at the time of diagnosis and/or registration. In fact, they even recommended that a specialist nurse should be on hand in the hospital out-patient department to provide a counseling and advice service, and to act as a source of information and advice. Attfield *et al.* (2006) identified that patients in general initiate information seeking to assess whether they need clinical intervention, in preparation for the patient-doctor consultation and to verify the diagnosis or treatment stemming from that consultation. They found that having confidence in health practitioners and the desire to use health service resources judiciously, efficiently and effectively were two key motivation factors for information seeking.

A.4 Quantity of information

The quantity of information needed by participants varied considerably, as did the extent to which these needs were met. For some participants, it was clear that they had received very little information about their visual impairment, other than being given a diagnosis:

"Well, none really." (A11, line 38)

"Very little ... apart from putting a label on what I've supposedly got ... nothing!" (B6, line 72)

"Erm ... very little because I've always been told there's very little they can do ..." (B9, line 79)

In contrast, other participants believed that they had received all the information that they wanted, as illustrated by the following quotes:

"Well, I think I've had all the information that's available ..." (A7, line 298)

"Oh, I've had all that macular stuff from Blind, love. I've got as much as I want to see." (A16, lines 125-126)

"... I've got all the information ..." (A10, line 134)

Miller (1987) identified that individuals faced with an aversive event, such as developing a visual impairment, differed in how they dealt with information about it. In this study, for example, some participants preferred to receive a high quantity of information (referred to as 'monitors' by Miller, 1987), whereas other participants preferred less information and distracted themselves from their situation (referred to as 'blunters' by Miller, 1987).

A.5 Quality of information

Only a few participants specifically referred to the quality of the information that they received from different sources (elaborated on under Theme B below), and most of these people seemed satisfied:

"Err ... it's been clear enough for me to understand ... yes." (B3, line 105)

However, it also emerged that some participants were concerned by the lack of quality information, particularly from the local hospital. The following quote illustrates this, especially how the quality of the information seemed to vary according to the health care professional seen:

"I usually have to ask those questions at the [hospital] ...and it really depends on ... the doctor and whether they're informed or not." (B3, lines 93-94)

Participants recognised the importance of being made aware of the strengths and drawbacks of different treatment options. Unfortunately this kind of information was not always provided by the health care professionals and instead participants had to seek out the information themselves, as illustrated by the following quote:

"Erm ... when I first went to the hospital last January ... I was just ... err ... presented with a form ... and this doctor said, 'You can have this film taken off by laser ... and it will help you' ... so I went home and thought about it ... and I thought ... yes it might ... but, on the other hand, no it might not ... and I need to know more about it ... but they weren't willing to volunteer more about it ...? I did have to go into it myself ... and I think that's what you've got to do ... not wait for them to volunteer information ... you've got to go ... armed with questions ... and ask for what you want to know." (B12, lines 216-233)

Another participant described the conflicting advice she had received and how this had affected the treatment options that were available to her:

"From the time I was diagnosed, because what transpired ... I should have had earlier attention. If I'd have gone a fortnight earlier, but they deferred me. They said, like, 'We don't want to see you for another fortnight'. Well, in that time, the nurse that saw me said, 'You should have come straight back. You shouldn't really have accepted. Gone home, thought about it ... and come straight back. You shouldn't have been allowed to have wait a fortnight, because that's really the critical period. You should really have been given some help with regard to laser treatment'. But she said, 'If I give you laser treatment now which you should have had previously ... err

... it would make you totally blind. You wouldn't be able to see'." (A15, lines 41-50)

Other participants expressed concern as to how the information was conveyed, particularly at the time of diagnosis by the ophthalmologists. The following quotes were typical of Group A participants' experiences and highlights the shock participants felt being told that there was no cure:

"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, lines 44-47)

"... and the favourite sentence ... and the one that was repeated by this lady ... was, 'You will definitely not go blind'. Now they should not do that ... they should treat you as though you are an intelligent person and tell you what is wrong ... so you can begin to face up to it. That is where I personally find ... found a lot of fault ... and so did many others." (A12, lines 221-226)

Other authors (e.g., van der Molen, 2007) have similarly indicated that it should not be assumed that the information provided to patients will necessarily be understood or retained. To reinforce the information provided, health professionals should supplement verbal information with information in a variety of different formats, such as written, visual and audio (van der Molen, 2007).

Participants raised the issue of the quality of information in connection with the information they sought themselves, particularly from the Internet. It was evident that participants, particularly those with a visual impairment since birth or early childhood, were deterred from using the Internet as a source of health and social care information because of concerns about both the quantity and quality of information available. This is demonstrated by the following quotes:

"I'd be a bit sceptical about medical information on the Internet ... because there's so much ... you could get ... err ... easily misdirected to ... err ... a web site that might have bad information ... so I wouldn't be confident in using web site information on medical matters." (B3, lines 190-193)

"I don't use it ... much for health. I'm overly cautious of what people put out there. And ... I know it's got some wonderful facilities on there ... but I know it's also full of ... lots of ... err ... nonsense." (B10, lines 184-187)

Another participant highlighted the problems she had deciding on whether a piece of information on the Internet was trustworthy and, therefore, found it difficult to find a definite answer to a question:

"... you get a lot of contradicting information on the Net ... and one report will say one thing ... and then the next piece of information will say something completely opposite ... you don't really know which is the reliable one." (B1, lines 122-124)

However, other participants described the techniques they used to assess the quality of the information that they found on the Internet. This ranged from only using "trusted" web sites, such as the RNIB, to comparing the findings from several different web sites:

"I try to go to more than one site ... so ... err ... sort of correlating what I've read with another site. Erm ... sometimes they contradict each other as well ... but, most of the time, they complement, so I'm fairly confident that the information given's correct." (B9, lines 231-234)

A.6 Access route

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). This classification is similar to that identified in published models of information seeking, in particular the different types of information seeking behaviour (passive attention, passive search, active search and ongoing search) identified by Wilson (1999). The majority of information, particularly in relation to participants' eye condition, health and social care services and facilities, and aids, adaptations and equipment, was received, mainly from health and social care professionals. However, many participants had either to seek additional information themselves, or they 'acquired' information from family, friends, local support groups and the mass media.

It was interesting to note that the majority of the information needs of Group A participants were met by the information they received. This may be because there were not aware of what additional information was available. However, it also emerged that most participants had 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)

"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, lines 48-49)

"... well, you've got to stifle your aggravation and ask for it ... otherwise I think you're just treated as an elderly person with an illness ... and a deficit ... and the least you'll know the better off you'll be ..." (A2, lines 229-232)

These examples also indicate the prevalence of the biomedical model, whereby patients are seen as passive beings to whom doctors "do" things (Nettleton, 1995) and where, in these cases, biological explanations of the eye condition took precedence over social, cultural and biographical explanations (Dixon-Woods, 2001). In general, the information provided to participants could be classified as "patient education", rather than "patient empowerment" (Dixon-Woods, 2001); the latter advocating the active involvement of patients in the information process.

In addition to acquiring extra 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); and money; and mobility. Much of the information participants acquired was from societies, organisations and support groups, friends and family, and the mass media. This is illustrated by the following quotes:

"It's people I know who've got problems with their eyes that have told me a lot" (A13, lines 68-69)

"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, lines 186-188)

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.

Finally, participants specifically sought information about their eye condition; the health and social care services and facilities; aids, adaptations and equipment; general health care; and benefits and money. Most of this information was obtained either by speaking to people or from the Internet. Participants from Group B tended to seek more information than people from Group A, as described in Theme C.2. 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. The following examples illustrate this point:

"I know what I need to know and that's it ... basically." (B2, line 63)

"No. To be honest, I don't know what I'd want anyway." (A14, line 71)

"... I've always thought I could ask the people at the [hospital] ... 'cos ... err ... they've got my medical file ... so ... err ... they can always consult it ... and ... err ... know any answers straight away." (B3, lines 111-113)

These examples also suggest that various other factors (e.g., a person's acceptance of their visual impairment, and the type of interaction with an information source) affected participants' information behaviour. This is elaborated upon under Theme C below.

A.7 Unmet information needs

Participants clearly had various unmet information needs, although, as noted by Nicholas (2000), these were not always explicitly recognised and stated by participants. Instead, these unmet information needs were often highlighted when participants described the difficulties they experienced in different aspects of their daily life, as illustrated by the following quote:

"... they're too numerous to discuss ... I mean ... there's lots of them ... so ... yeah ... I mean ... the daily things which most ... err ... normal sighted people take for granted are a problem ... err ... that's perhaps the best way of summing it all up really." (B6, lines 112-116)

It was also clear from participants' comments that a lack of accessible information was partly to blame for these difficulties.

In general, participants' unmet information needs reflected the information participants sought, and related to each of the eight types of health and social care information identified above. Before considering these information needs in more detail, it is important to note that some participants felt that their information needs had been met, whilst others simply did not want to know anything more about their visual impairment:

"But I honestly don't think there's anything more I can ask." (A7, line 150)

"Well, I suppose I've been rather fortunate in that ... most of ... the advice I've had ... and received ... either ... whether it's been printed ... or verbally ... erm ... has coped with most of my enquiries." (A3, lines 277-279)

"No, I'm not bothered. What I don't know can't ... harm me. I suppose ... in some ways I'd rather not know." (A11, line 71-72)

Some participants did acknowledge that their additional information needs could be met, *i.e.*, that the information required was available and it was just a case of seeking it out:

"It's no good waiting ... for people to come to you. There is information there for you ..." (A10, lines 155-156)

In terms of unmet information needs about the eye condition, the interviews indicated that one of the major areas overlooked by health and social care information providers was the causes of different visual impairments, as illustrated by the following quote:

"I think I got all the information that was available. Didn't occur to me to ask for any more ... except to ask why ... what was causing it." (A7, lines 138-139)

Many participants had various unanswered questions relating to the cause of their visual impairment, in particular whether there was a genetic or dietary link:

"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, lines 227-228)

"I wonder whether it was due to my mother having had German measles when she was pregnant." (B4, lines 9-10)

"Whether you can still develop glaucoma with macular, I don't know. Or ... can you still get cataracts ... you don't know." (A13, lines 200-202)

"Somebody told me it was food ... I never heard anything like it in me life. Telling them it's food." (A16, lines 198-200)

It was also evident that a few people were not sure of their diagnosis or why they were being referred to the ophthalmology department:

"I would have liked to have known ... what it actually was." (A13, line 76)

"... I don't think he mentioned macular then ... he just said, 'Go straight away'. And ... err ... I'd no idea really what I was going for." (A1, lines 9-15)

Other participants obviously had unmet information needs relating to the prognosis of their eye condition:

"Well, I'd like to know impossible ... but you know what that is, don't you? Am I going to go blind? Or ... can I stop as I am." (A10, lines 79-80)

It was also clear that some people did not feel that they were provided with a complete picture of their eye condition and the treatment options available to them. This is illustrated by the following quotes:

"I don't know what progress has been made in terms of treating this ... whether treatments are likely to become available in the near future ... are there ways of improving ... err ... you know ... what's there at present ... or ... err ... perhaps ... even ... err ... sort of retarding any future degeneration ... I've had absolutely no information at all." (B6, lines 77-81)

"Had I known more when I had my first ... examination and they told me there was nothing they could do. I didn't know that there was ... any treatment. If they had told me that there was treatment but you had to pay ... I would have done so ... at that time." (A13, lines 5-8)

Although it was noted previously that most participants were aware of the health and social care services available to them, it also emerged that there remained a need for better dissemination of information about these kinds of services; for example:

"err ... what help you can get with regard to what societies there are in the Sheffield area ... that specifically deal with matters connected with macular." (A15, lines 8-10)

Participants had a few unmet information needs relating to aids, adaptations and equipment, as demonstrated by the large number of participants that acquired relevant information, rather than being told about these devices automatically.

It was clear that participants had a range of unmet information needs relating to general health care, in particular reading medical information, such as appointment letters, prescriptions, medicine labels, hospital notices and signs, etc., as illustrated by the following quotes:

"... 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, lines 14-15)

"... and you will find in a lot of places ... you can find lots of things in ... lots of other formats ... but nothing in Braille. For instance, doctor's waiting rooms ..." (B7, lines 280-282)

"err ... I have taken medication ... so ... err ... yeah, the instructions are always minutely printed ... so ... err ... it's not great ... sometimes the writing's ... err ... so small ... that even a magnifying glass isn't that much help." (B9, lines 119-122)

A few participants specifically referred to the problems they encountered when administering medications, in particular taking tablets:

"You mean, tablets like? I've had no end of problems with them. I don't know what I'm taking. I'm on so many, you see ... When you're on so many different drugs ... it's easy to get confused." (A11, lines 80-83)

These findings are supported by previous research; for example, Bruce and Baker (2001) found that thirty per cent of respondents (N=1,076) with 'uncorrectable' sight problems were not able to read medicine labels or doctors' letters, while a further 40% found it difficult. Grills and MacDonald (1997) found that visually impaired people encountered difficulties opening containers, administering eye drops and measuring liquid doses.

It was evident that some participants were unaware, or unclear, of the financial benefits they were entitled to, thus highlighting a possible unmet information need; for example:

"But they don't get pensions for blind, do they?" (A6, lines 46-47)

Participants also experienced difficulties completing forms in order to apply for financial benefits. This resulted in them either asking for help from others, or, rather worryingly, not going ahead with an application.

"The other thing is filling in forms. That is not easy. Often the print is wrong ... err ... you know, getting in the right square ... when you can't focus"

probably can sometimes be difficult ... if you're doing it yourself ... which means either you don't do it, or you have to ask someone else to do it." (A17, lines 304-307)

Money recognition and having to trust other people to help with this task posed a particular problem for several participants:

"... money's another problem ... coins ... you know ..." (A13, line 124)

"Even when I go to the chemists they know they have to take the money now ... I have to trust them ... I just can't tell." (A11, lines 83-85)

A few participants also referred to the difficulties they encountered when using cash machines and how overcoming these problems jeopardised their confidentiality:

"... how can you do it ... without anyone seeing ... how can you do that when you can't feel it ... it's all plush ... all flat surfaced ... so ... you can't even feel the buttons to push them ... all these new technologies might be nice for some ... but not too good for others." (B8, lines 307-310)

Many participants described the mobility problems they encountered, such as using public transport. These ranged from reading timetables and display boards to locating the right platform and flagging down the right bus. For example:

"... reading timetables ... yes ... that information I find ... err ... is not easily available to me ... I usually have to ask somebody to find it out for me ..." (B3, lines 144-145)

Participants exhibited a number of coping strategies. Examples include enlisting the help of other people to read travel information for them and writing the required bus number(s) on a piece of card to hold up to bus drivers while waiting at a stop, as illustrated by the following quote:

"... my husband made me a big piece of card, like that, with the number of the bus I was ... so that when I was at a bus stop ... I could hold this up for the driver to see ..." (A3, lines 293-295)

Most of the participants also suggested solutions, or partial solutions, to some of their travel difficulties; for example, providing spoken announcements at bus stations, making timetables in alternative formats, etc.

Going away or on holiday proved a particular problem for some participants, particularly those with mobility problems. The following Group A participant explained how this also added to her feelings of social isolation:

"I suppose my biggest problem is getting out ... and going on holidays. You see, although they do these organised trips ... I need a wheelchair ... and they're not interested when you tell them that. I mean, I can understand it, but it does mean you're ... left out." (A14, lines 77-80)

Several participants referred to the difficulties they encountered when going out to eat or to shop, in terms of not being able to read menus and labels, as well as navigating their way around restaurants and shops.

"Like when you go to restaurants and café's ... you can't read menus and things." (B1, line 103)

In order to address their information needs in this respect, participants were generally dependent on support from friends and family; for example:

"... and you have to get someone either within the shop ... come and help you ... or ... go with someone ..." (B2, lines 96-97)

Participants also indicated that they had information needs relating to housing and accommodation, particularly performing household chores, such as cooking, clothes washing, cleaning and gardening. In terms of cooking, for example, participants faced problems when preparing food, identifying food packages, reading recipes and cooking instructions, and using cookers. This is illustrated by the following quote:

"... like cooking instructions ... erm ... there're a problem ... err ... tins is a problem ... err ... what else? ... just general things ... if things are in jars ... that's a problem ... err ... it's not the actual cooking of what you want to eat ... it's just knowing how long to cook it for ... and ... erm ... what temperature it's got to be on..." (B2, lines 86-90)

It also emerged that in order to address these problems, participants generally had to do something about it themselves, such as hire their own home help independently:

"So ... I-I've now got someone ... BUT ... it's under my own ... err ... remission that I've ... I've got this ... and no-one from Social Services ... can do anything about it ..." (A1, lines 188-190)

Another participant was frustrated with herself for not seeking help in this respect:

"I mean ... I suppose I can get help for all these things ... cooks with bigger numbers put on ... I wish ... my own fault I've not got in touch with anybody." (A13, lines 57-59)

Finally, for some Group B participants, information about employment, education and training opportunities was lacking. The following participant described the problems her visual impairment caused her in terms of trying to find paid employment:

"So many jobs these days ... use PCs ... or even when answering 'phones ... they're silent ... they show a light, but don't make a noise ... which is obviously a problem for me." (B4, lines 64-66)

To conclude this section, these interviews suggest that the majority 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, 1998b; Hall *et al.*, 2000; RNIB, 2001c; 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, 1997b; Masey, 1997). The implementation of the *Disability Discrimination Act 1995* (Office of Public Sector Information, 1995) should hopefully have helped in this respect.

Theme B. Sources of health and social care information

The interviews revealed that participants obtained their health and social care information from six major sources, as shown in Figure 4: 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 society for the blind, local visual impairment support groups, and national visual impairment organisations); friends and family; school and the mass media (*i.e.*, television, radio, (talking) newspapers and magazines, *etc.*). In addition, the interviews explored participants' opinions about newer sources of information, such as NHS Direct, touch screens and the Internet, as well as participants' preferred information source for health and social care matters.

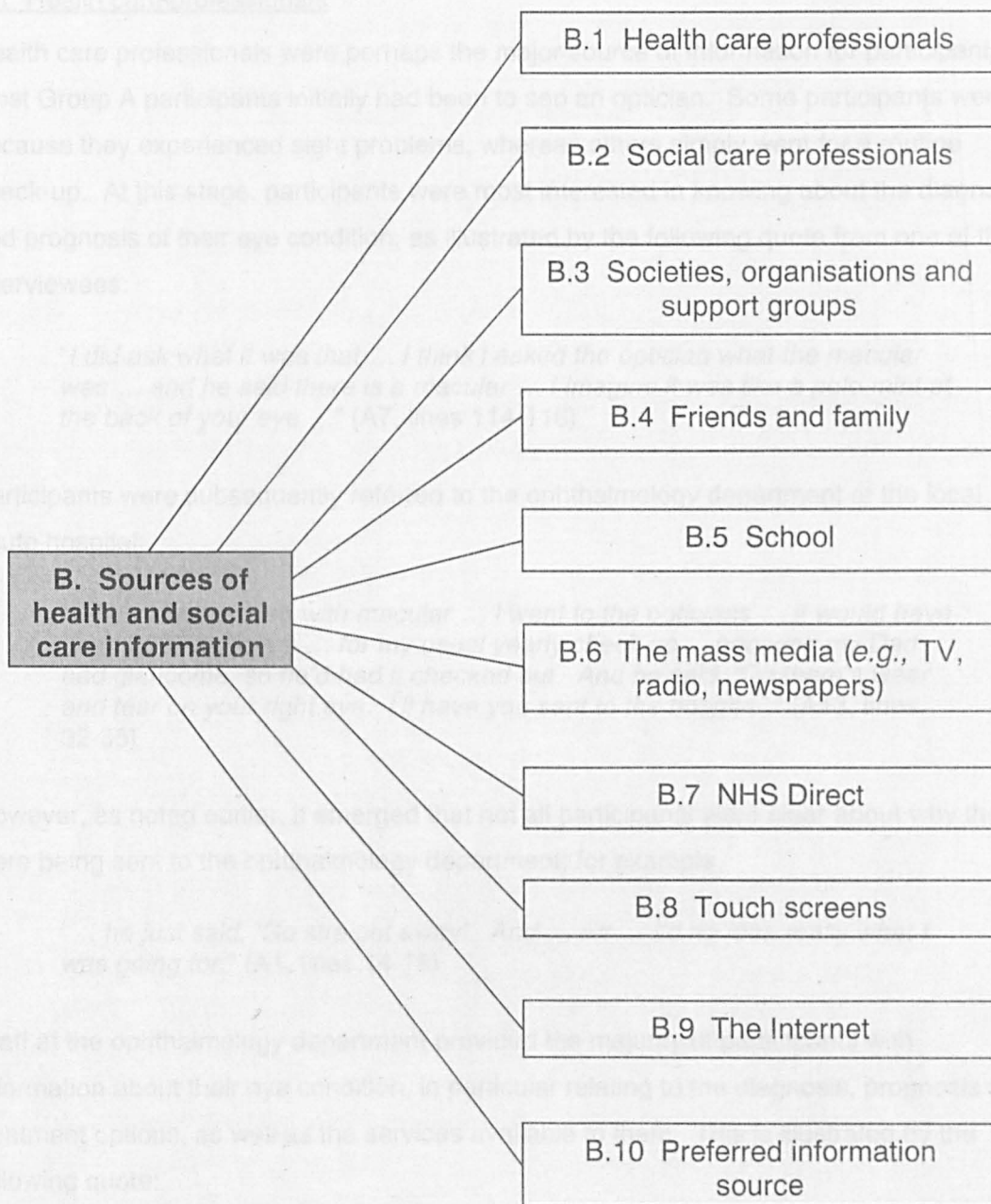


Figure 4. The interview sub-themes of Theme B 'Sources of health and social care information'

B.1 Health care professionals

Health care professionals were perhaps the major source of information for participants. Most Group A participants initially had been 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, as illustrated by the following quote from one of the interviewees:

"I did ask what it was that ... I think I asked the optician what the macular was ... and he said there is a macular ... I imagine it was like a polo mint at the back of your eye ..." (A7, lines 114-116)

Participants were subsequently referred to the ophthalmology department at the local acute hospital:

"When I first started with macular ... I went to the opticians ... it would have been 2002 in March ... for my usual yearly check-up ... because my Dad had glaucoma, so he'd had it checked out. And he said, 'Oh there's wear and tear on your right eye. I'll have you sent to the hospital'." (A13, lines 32-35)

However, as noted earlier, 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, lines 14-15)

Staff at the ophthalmology department provided the majority of participants with information about their eye condition, in particular relating to the diagnosis, prognosis and treatment options, as well as the services available to them. This is illustrated by the following quote:

"They tell me which way ... what I'd got, which way it could go. There is no cure for glaucoma ... they can try and control, but at same time ... it is possible for, you know ... the eyesight to go. Err ... I've had every help ... from eye clinic, me consultants ... err ... his nurse ... nurses what do your eye testing ... glaucoma unit ... even when I come out of operating theatre ... in day surgery ... I've just had nowt but help ... and information." (A10, lines 58-63)

Several participants commented on how they thought the situation had improved in recent years, particularly with the introduction of an "information booklet" at the hospital:

"... erm ... I think this is a lot better now ... in the ... in respect of the fact that ... you do get answers ... whereas many years ago ... erm ... when doctors thought you shouldn't know things, you didn't get to know everything ... for some reason." (B12, lines 213-216)

"Yes, we got that ... big book ... yellow book, didn't we? ... The Specialist gave a big book on what I could do, what I couldn't do, and what I could get, you know ..." (A4, lines 87-89)

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. The majority of participants appeared to be satisfied with the information that they had received from the low vision clinic:

"... they've been great with me ... err ... everything what were available to me was explained ..." (A10, lines 68-69)

However, it was evident that referral on to the low vision clinic was not automatic and some participants were not even aware of the service. For example:

"Err ... low vision ... where's that?" (B3, line 45)

"I was speaking to a chap ... he said to me, 'You know, I wish I knew more about it'. Well, I said, 'Ask her ... when you go in for your assessment ... for your visual aids ... whatever you want ... ask her about it', because somehow, I said, 'If you don't ask, you won't get to know ... what help is available'. And that low vision clinic should come automatically when you've had your assessment because you want help with your sight ... you know ... your problems." (A15, lines 18, 21-26)

Finally, a few participants specifically mentioned seeking information from their GP. However, one participant expressed concern about their GP's lack of specialist 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, lines 109-110)

B.2 Social care professionals

Participants also received information from a variety of social care professionals, including social workers and other care workers, as well as from individually hired home help.

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. This is illustrated by the following quotes from two participants, one with an age-related visual impairment, and one with a visual impairment since birth or early childhood:

"But the Social Services have been very good to me, especially one lady. Err ... she ... took me out stick training ... we have sticks ... white stick and stuff. And then she introduced me to a group of ... like people ... who are all visually impaired." (A4, lines 34-37)

"I'm still in touch with ... Social Services. For example, I've had a lot of ... erm ... mobility training ... you know, finding my way around ...err ... and I do get some aids from them ... for example, I get my canes from them. I've had ... err ... I've had err ... like a talking microwave from them ... erm ... and also ... what else? ... one of those liquid level indicators ... to help you pour tea into cups ... err ... I've had that." (B13, lines 53-54, 56-59)

However, there was some confusion about the initial method of contact with Social Services; for example, many participants had to contact Social Services themselves, as demonstrated by this comment:

"... Social Services ... I've had to ask all the time ... and I've had to find out for myself." (A12, lines 366-367)

In addition, a few participants had hired their own home help. It was clear that these people were also acting as a valuable information source to these participants, particularly in terms of reading correspondence and filling forms out, even though this did not constitute a formal part of their job description.

"... err ... my home help ... she can often answer me questions ... help me read correspondence ... you know?" (A14, lines 71-73)

Although social care professionals certainly had a role to play in meeting participants' information needs, their relative importance over other information providers identified in this study was noteworthy. This may be because in Sheffield many of the social care services are outsourced to the local society for the blind. It would be interesting to see if Social Services have a more prominent role in information provision in other parts of the UK particularly where such arrangements do not exist.

B.3 Societies, organisations and support groups

Various national and local societies, organisations and local support groups catered for a variety of participants' unmet information needs. The local society for the blind, for example, was a major source of information for participants and directed users to appropriate health and social care services, offered advice about financial benefits, provided practical assistance in filling forms out, organised social events, arranged talking books, and advised on the availability and use of aids, adaptations and equipment. Overall, participants were very satisfied with the information and support provided by the local society for the blind, as illustrated by the following quotes:

"... they're very well versed ... they have all the knowledge and they are very very good at dispensing it if you ask for it ..." (A2, lines 309-310)

"I find them very helpful." (B6, line 45)

However, it emerged that some participants had heard about the society via friends and family, rather than through formal channels. For example:

"... someone gave me a number to bring the Blind ... but that was nobody ... that was a lady at the golf club who's just started with it ... and she gave me this number to ring." (A13, lines 121-124)

Local support groups also had a valuable role to play in the social lives of some participants, ensuring that they could continue with their hobbies, etc. These groups also served to meet some of the participants' information needs, as illustrated by the following quote:

"... I'm a member of the [local] Macular Disease Society ... so I'm getting information all the time ... on tapes ..." (A12, lines 241-242)

Other organisations mentioned by participants included the RNIB, St. Dunstan's and the Guide Dogs for the Blind Association. For some participants, these organisations were an important source of information and support on social care matters.

B.4 Friends and family

Friends and family were a valuable source of 'acquired' information for many participants. For example:

"Yes, it was a friend who sent me something out of a ... magazine ..." (A7, line 125)

For one participant with an inherited eye condition, her family was *the* major source of information:

"Well, most of my family are blind ... so ... about 50% really ... and ... because we're all like it ... everybody helps each other out ..." (B1, lines 42-43)

Finally, many participants were dependent on family members to help them read written information received from other sources.

"Well ... err ... my parents help me with that ... you know ... if I get any post ... I either ask them to read it if ... err ... if I'm going to see them sometime soon ..." (B3, lines 84-85)

B.5 School

For some Group B participants, schools were responsible for raising awareness of health and social care services available to visually impaired people. For example:

"Erm ... I think it was through ... err ... school actually. Erm ... this woman from Social Services ... she did a lot of work at school ... and she put my mum in touch with them ... the [local society for the blind]." (B2, lines 35, 37-40)

B.6 The mass media

Participants acquired information about eye conditions, new treatment options and health and social care services from a variety of local media sources (e.g., Sheffield Talking News), as well as national media sources (e.g., New Beacon, the RNIB magazine, and BBC Radio 4's 'In Touch' programme). For example:

"... I hear a lot of things through the ... Talking News ..." (A1, lines 489-490)

"... there was a big article in The Star about macular ... people complaining about ... going blind because of the cost of the treatment ... and ... I saw this thing about the blood vessels ... and I thought that's me ... that's what I've got ... nobody had explained it ..." (A13, lines 104-107)

"... I did hear on a radio programme over in the United States that they had done an operation on one person ... and ... they could see ... what 10 feet in front of them ... and 8 feet to the side ..." (B7, lines 40-43)

Several participants, however, recognised the potential bias of information reported by the media, yet still hoped the claims would turn out to be true:

"... you know all the stuff that got reported in the press was as usual biased ... you know, only get half the story ..." (A17, lines 167-168)

"... because of hearing ... you know ... the news items on television ... and they blow it all up ... and you know quite well they are doing ... but you still wonder ... of various miracle cures going off round particularly in America ..." (A12, lines 183-185)

B.7 NHS Direct

Many participants had never heard of NHS Direct and even fewer people had actually used the service. Interestingly it emerged that several of these participants were in fact aware of NHS Direct, but had either forgotten about it, or had decided it was not relevant to them. For example:

"I've heard of it, but I've completely forgotten about it ... obviously not been plugged enough." (B9, lines 195-196)

"Well, I've heard of it, but I didn't think it applied to me." (A7, line 211)

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 quotes:

"Ooh, can you put it me in my book then?" (A6, line 124)

"No, I've not heard of it. Oh ... oh ... that sounds handy!" (A1, line 425)

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:

"Erm ... it's a good idea in theory ... but ... if somebody's on other end of telephone and somebody's like needing medical attention ... they can't diagnose the problem without seeing that person face-to-face. So I think it's a good thing in ... err ... in theory ..." (B2, lines 111-114)

For those participants that had used NHS Direct (for health conditions unrelated to their visual impairment), they were generally satisfied with the information and/ or advice they had received:

"I've found that to be absolutely marvellous. You know ... really really fantastic ... err ... because it's a voice. Erm ... yes ... I've found they deliver a fantastic service ..." (B10, lines 164-166)

These findings, therefore, suggest that NHS Direct is not being promoted sufficiently to visually impaired people, even though it offers obvious advantages over traditional written health information for this group. Alternatively, it may be that the public perceive NHS Direct as an out of hour's alternative, rather than an information source. Given participants' preferences for face-to-face information (see Theme B.10), services, such as NHS Direct, should, therefore, be seen as supplementary to the health information sector, rather than an alternative.

B.8 Touch screens

On the whole, participants were sceptical about using touch screens for accessing health and social care information, mainly because of concerns about knowing where to touch the screen:

"Well, I wouldn't be able to see where to touch ..." (A14, line 116)

However, several participants said that they would be prepared to try using a touch screen to access information, as illustrated by the following quotes:

"Well, I haven't come across these ... but I should imagine I would give them a go ... yes." (A3, lines 235-236)

"Err ... I'd consider experimenting with them ..." (B3, line 202)

No participants had used a touch screen to access health or social care information, but several participants had accessed other information, such as travel information, via a touch screen. Some of these participants indicated that they found them difficult to use because they could not read the screen. Interestingly, a few Group B participants gave suggestions as to how touch screens could be made more 'user friendly' for visually impaired people. This included having an in-built speech function.

"... nowadays ... there's no reason why they shouldn't have speech on them ..." (B10, lines 221-222)

For touch screens to become a viable information source for visually impaired people, adjustments would need to be made; for example, by supplementing written information with spoken information. However, this raises important confidentiality issues. For example, if the touch screen was in a public location, such as a doctor's waiting room, pharmacy, supermarket or library, then the person using it may feel uncomfortable about others knowing what they were searching for, particularly if this was of a highly personal or sensitive nature.

B.9 The Internet

Opinions about the Internet as a source of health and social care information varied considerable, and often concerned the quality of information available, as discussed under Theme A.5. The following quotes were typical of many participants:

"That's a swear word to me! It really frustrates me." (B4, line 135)

"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, lines 898-899)

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. Some of these points are highlighted in the following quotes:

"Well my eyes are that bad that I wouldn't be able to see ... and I've got enough difficulties with everything else." (A11, lines 107-108)

"Oh I am interested ... I'm incapable of doing. I would need too much expensive equipment ... if I were being truthful." (A5, lines 574-575)

Several other authors (e.g., Capel *et al.*, 2007; Douglas *et al.*, 2007a), as highlighted in Chapter 2, have found similar barriers to Internet use, particularly amongst older people.

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. For example:

"... not being able to use the computer for the Internet is a big obstacle, because there's so much information available but if you can't read it it's another matter." (A15, lines 105-107)

Of those participants who did use the Internet, many used specialist software, such as screen readers, to help them access relevant information. Participants generally used generic search engines, such as Google, to search for health and social care information:

"Erm ... to be honest ... my first port of call is Google ... and I just do a search for whatever I want ..." (B9, lines 218-219)

There is, therefore, clearly scope to increase knowledge and awareness of specialist Internet resources to visually impaired people. For example, NHS Direct and, more recently, NHS Choices, provide high quality peer-reviewed information on different eye conditions, yet NHS Direct was rarely used by participants. Instead, participants were faced with trawling through lots of web sites, of varying quality and accuracy. However, it is important to acknowledge that, as noted in Chapter 2, Internet awareness and use amongst visually impaired people, particularly older visually impaired people, remains low, and the various barriers to access must be overcome before it can be truly considered a viable alternative information source for health and social care information (Williamson *et al.*, 2001; Capel *et al.*, 2007; Douglas *et al.*, 2007).

B.10 Preferred information source

Participants' preferred information source for health and social care information varied considerably. However, most participants stated that they would prefer to speak to a person, whether that was 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. This is illustrated by the following comment by one of the interviewees:

"Err ... I-I think if I've got a health issue I'd rather speak to a doctor ... or somebody on the 'phone." (B10, lines 187-188)

It was clear from this study that participants were dependent on a wide variety of sources in order to obtain the information that they required. It also highlights the importance of

organisations, societies and support groups, such as the local society for the blind, in meeting the information needs of visually impaired people: organisations, societies and support groups provided participants with information in each of the major health and social care areas identified. Similarly, the Internet has the potential to meet a large proportion of visually impaired people's information needs. However, this requires more active information seeking by the person with a visual impairment which, as alluded to before, may prove problematic for some people. Interestingly, Donnelly (1997a) advocated having dedicated and trained members of staff who could provide information, advice and counselling to visually impaired people.

Theme C. Factors affecting information behaviours

The interviews, as shown in Figure 5, identified a number of factors which could potentially affect a participants' information behaviour. These related to the presence of other health conditions and/or disabilities; the type, length and registration of visual impairment; participants' degree of independence; the support participants received from friends and family; participants' acceptance of their own visual impairment participants'; participants' willingness and ability to pay for aids, adaptations and equipment; the extent to which participants could be regarded as an "expert patient"; participants' understanding of the word 'information'; and participants' interactions with information sources. Although not identical to, there are definite parallels between the factors identified in this study and Wilson's (1999) intervening variables. This is discussed in more detail in Section 8.3.2.

C.1 Presence of other health conditions and/or disabilities

As noted in Section 4.4.5.2, the majority of participants also experienced one or more other health conditions and/or disabilities, such as arthritis and hearing impairments. It was evident that, for many participants, these additional conditions and disabilities further hindered their lifestyle and information behaviour; for example:

"And ... so ... I've been cut off secondly ... with my arthritis ..." (A1, lines 85)

"Erm ... so ... I-I tend to lump the two handicaps together because one hinders the other ..." (B12, lines 40-41)

"I've got the triple whammy here ... because not only that ... but also the eyes and the ears ..." (A12, lines 617-618)

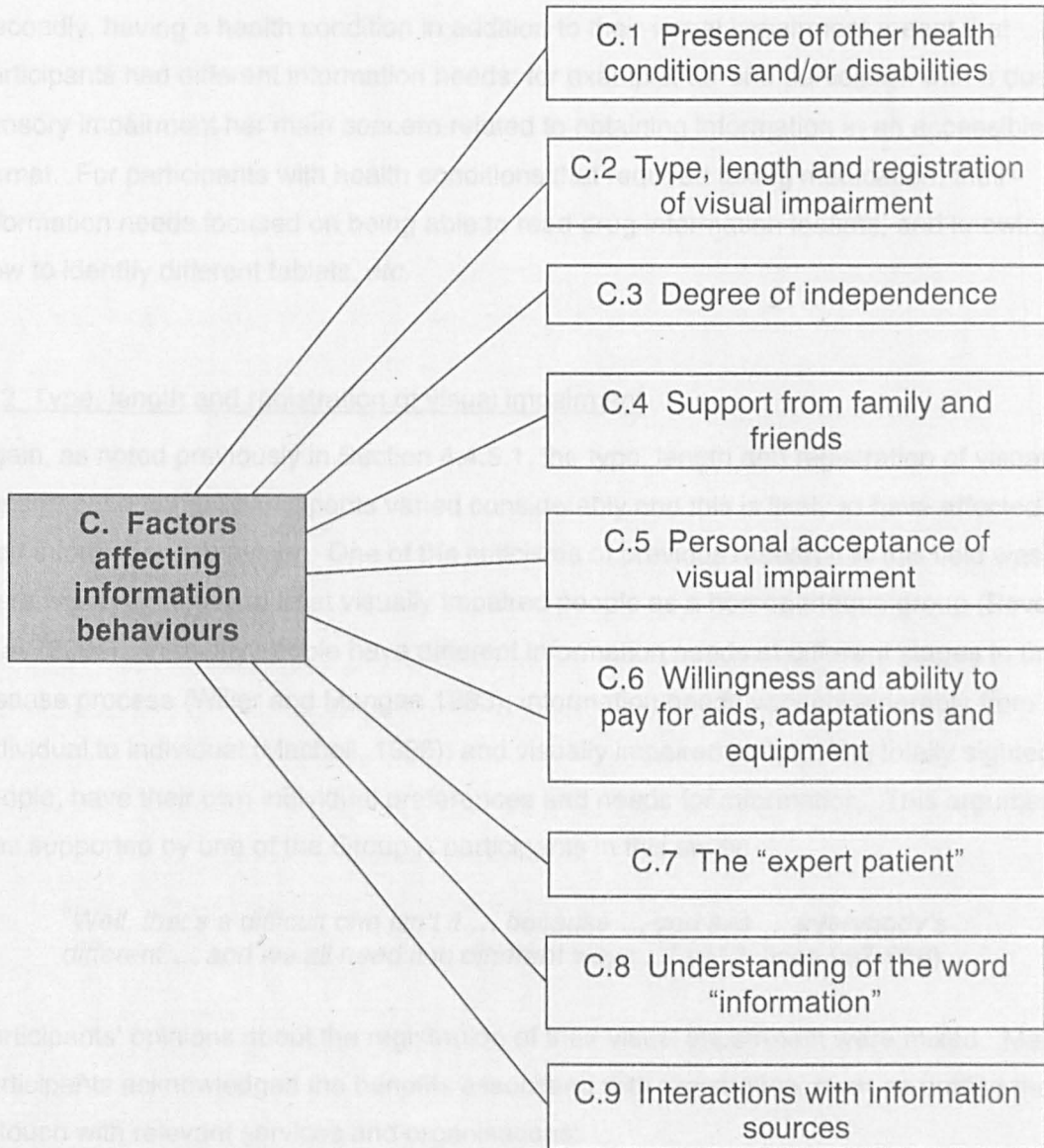


Figure 5. The interview sub-themes of Theme C 'Factors affecting information behaviours'.

The presence of other health conditions and/or disabilities meant that participants were more likely to come into contact with health and social care services. Their information

behaviour was probably affected in several ways as a result of this. Firstly, by visiting health and social care professionals more regularly this provided participants with greater opportunity to ask questions about either their visual impairment or other health conditions. Secondly, having a health condition in addition to their visual impairment meant that participants had different information needs: for example, for one participant with a dual sensory impairment her main concern related to obtaining information in an accessible format. For participants with health conditions that required taking medication, their information needs focused on being able to read drug information leaflets, and knowing how to identify different tablets, *etc.*

C.2 Type, length and registration of visual impairment

Again, as noted previously in Section 4.4.5.1, the type, length and registration of visual impairment amongst participants varied considerably and this is likely to have affected their information behaviour. One of the criticisms of previous research in this field was that there was a tendency to treat visually impaired people as a homogeneous group (Beverley *et al.*, 2004). In reality people have different information needs at different stages in the disease process (Willer and Mangan 1983); information needs vary considerably from individual to individual (Machell, 1996); and visually impaired people, like totally sighted people, have their own individual preferences and needs for information. This argument was supported by one of the Group A participants in this study:

"Well, that's a difficult one isn't it ... because ... you see ... everybody's different ... and we all need it in different ways ..." (A12, lines 967-968)

Participants' opinions about the registration of their visual impairment were mixed. Many participants acknowledged the benefits associated with registration, such as putting them in touch with relevant services and organisations:

"... oooh and I'm registered. It opens doors ... it opens doors ... and without 'em we'd be lost." (A10, lines 174-175)

However, it was also clear that registration was not automatic, with a few participants not even being aware of the process:

"Do you get registered ... what with your sight, you mean ... being blind?" (A13, line 128)

This interview study attempted to examine the similarities and differences between two groups of visually impaired people: those with an age-related visual impairment (Group A) and those with a visual impairment since birth or early childhood (Group B). 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.

Firstly, Group A participants tended to rely more on the information that they received and were less likely to seek information independently themselves. However, they were probably more aware of their unmet information needs, suggesting that their needs were not being fully met but that they did not know where to seek additional information from. In contrast, Group B participants were more active in seeking the information they required, but generally had fewer unmet information needs, suggesting that they had been able to address most of their information needs independently. This may, of course, be because the Group B participants had had longer time to seek out the information they required.

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 favourable towards using the Internet to search for health and social care information. This may be due to 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. Having said that, some of the most active Internet users were elderly participants with an age-related visual impairment.

Participants from Group B raised the issue of alternative formats considerably more than Group A participants. As noted previously, these participants expressed a preference for information to be provided in Braille, whereas Group A participants preferred to receive information either in large print or on audio tape. This is probably because most people with a visual impairment since birth or early childhood were taught Braille at school, whereas there was limited opportunity for older people to learn Braille. This finding is in line with previous research in the field (RNIB, 1998b).

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, as illustrated by the longer duration of the interviews with participants from this group. Since these findings should be transferable to similar groups, as discussed in Chapter 8, then this information should prove helpful when planning future research with visually impaired people.

C.3 Degree of independence

Some participants were clearly very independent and did not want to have to rely on other people in order to address their information needs, as illustrated by the following quotes:

"... and I only let people do for me what I can't manage myself." (A2, line 28-29)

"I don't want to have to depend on other people." (B4, lines 14-15)

A few participants commented on how having a guide dog had helped to increase their independence:

"And, of course, having my dog ... means I can get out." (A4, lines 38-49)

In contrast, other participants acknowledged that their visual impairment had caused them to lose some of their independence. For example:

"And then ... from then on ... all my independence really had gone ... I'm now ... you know ... dependent on other people ..." (A1, lines 53-54)

C.4 Support from friends and family

Friends and family were a major source of support (as well as information, as discussed under Theme B) for participants in this interview study. The lack of this kind of support was clearly noted by some participants, particularly those from Group A:

"And if you don't have any relatives, it's God help you." (A2, lines 472-473)

"Loneliness is a disease, you know ... loneliness is a disease ... and don't you forget about that. You need to do some research into that." (A2, lines 534-535)

The latter quote also highlights the additional difficulties and psychological burden of having a visual impairment and living alone.

It also emerged from the interviews that, although some participants enjoyed socialising with other visually impaired people, one Group B participant in particular was adamant that she did not want to do this:

"... but I don't want to get on the blind conveyor belt. I want to mix with sighted people. I was brought up with sighted people." (B4, lines 116-117)

C.5 Personal acceptance of visual impairment

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, as illustrated by the quotes below:

"... I've been blind, you know, most of my life ... and I'll be blind for the rest of my life as well, so ... it's just something that I accept and I get on with." (B13, lines 22-24)

"I mean if you can't see ... you can't see!" (B8, line 514)

"I think you've got to take responsibility for your own life ... and use what information you can." (B12, lines 242-243)

Many Group B participants had developed various coping strategies. These included developing their memory skills more, as well as adopting systematic approaches to a variety of daily tasks (e.g., washing). The following quote demonstrates one such coping strategy:

"When you don't see ... you remember things ... you use your memory a lot more ... you know ... not just a bit more ... a hell of a lot more ... because it's how you navigate and get around." (B10, lines 137-139)

It was clear that for Group A participants accepting having a visual impairment was harder, but that they too had gradually learnt to overcome the shock:

"Everything frustrates me now. It started off with not being able to see ... err ... you know ... I wasn't a patient person ... but I'm learning and having to learn to be patient with myself." (A7, lines 271-274)

However, it was also evident that many participants had yet to come to terms with their visual impairment fully:

"... you know ... you cope with it ... as best you can ... but ... it still doesn't mean you don't appreciate someone caring enough about you ... you know ... and you sit there and you wonder what you're doing wrong." (A12, lines 426-428)

The psychological impact of having a visual impairment was apparent in the comments made by many participants. For some people the speed of onset of their visual impairment and the initial shock of being diagnosed as blind or partially sighted were particularly difficult times.

"It was all a bit of a shock though ... on Saturday I could see ... but by the following Monday, I couldn't ... and then my legs went as well. It was ... still is ... a very difficult time." (A14, lines 50-52)

"To be truthful ... the first 6 months was ... oohhh ... I didn't know ... you see, I went blind in three days ... virtually ... from having reasonably perfect vision and I did go for a small time ... totally blind ... It's a very ... scary thing." (A4, lines 70-73)

For other participants, it was the impact having a visual impairment had on their lifestyle, particularly their social life, that they found most difficult:

"cos I've always had ... as you can tell ... a very busy social life ... and ... to have it suddenly taken away is very hard." (A12, lines 402-403)

"I used to do all sorts of things ... sewing, dress-making, tailoring and making hats ... painting and everything ... you know, all the crafts ... pottery ... and, of course, I can't do any of them now ..." (A7, lines 25-27)

These findings are in accordance with previous research in the field described in Section 2.3.10 which has explored the effects, particularly the psychological impact, of having a visual impairment.

Several participants commented on how they were keen to try new approaches in order to adapt to being visually impaired, as illustrated by the following quotes:

"... a lot depends ... on adaptability." (A15, line 352)

"The thing is ... I'd sooner try and fail than not try, you know?" (A4, lines 181-182)

"You hear too much about what you can't do ... it's amazing what you can do, if only you give it a go." (A5, lines 657-658)

However, it was also clear from the interviews that a few people coped by refusing to find out more information about their visual impairment:

"What I don't know about, darling, I can't worry about. I know that my eyes won't get any better, my health won't. But I accept each day as it comes. I live a day at a time now." (A2, lines 341-343)

These findings suggest that participants followed a similar process to adjusting to visual loss, as described by Crossland and Culham (2000); that is, some participants referred to the shock and/or denial that they initially experienced, other participants referred to the subsequent depression and realisation of all the things that they could no longer do; whereas, a few participants, had now reached the acceptance stage and had come to terms with their visual impairment and its implications.

C.6 Willingness and ability to pay for aids, adaptations and equipment

Participants' willingness and ability to pay for aids, adaptations and equipment affected their information behaviour. For example, if participants were willing and able to pay for such items then they tended to seek out information actively about these devices. However, it was clear that the additional costs faced by visually impaired people were a major barrier and frustration for some participants, as illustrated by the following quotes:

"... they're really quite expensive ... the equipment ... in fact ... looking it at it cynically ... a lot of these companies are making a lot of money out of people who are disabled ... and I don't agree with that either." (A12, lines 791-793)

"... you're looking at about £1,000 ... err ... and so that's really not accessible to the average person ... particularly if you're out of work." (B10, lines 286-288)

C.7 The "expert patient"

It emerged that several of the participants had acquired 'expert' knowledge about their visual impairment and the services available to them; for example:

"It's congenital macular dystrophy ... or ... more commonly known as Stargot's disease ... which basically ... erm ... it affects the ... err ...

macular ... area of vision ... of the retina ... destroys it effectively ... (B6, lines 6-8)

... I cannot register as partially disabled ... or disabled because the reading ability in this eye is still slightly just above the minimum requirements ... (A17, lines 147-149)

These people were, therefore, often sources of information for others, such as via local support groups, and did not generally seek much new information themselves.

Many participants exhibited considerable awareness and appreciation for different types of visual impairments, particularly the distinction between being totally blind and partially sighted and how this affected people's information needs. This is illustrated by the following quote from an interviewee who, after many years of being partially sighted, was now blind:

... being partially sighted and being blind is a gulf ... this wide. (B5, lines 308-310)

As noted by Attfield *et al.* (2006), the concept of an expert or 'informed patient' is becoming more prominent, particularly as a result of the growth of health information on the Internet. Similarly, the national 'Expert Patient' programme has shown that people with chronic illnesses can use their knowledge and experience in positive ways and need not be mere recipients of care (Capel *et al.*, 2007). On the one hand, this has resulted in concerns about associated changes in the doctor-patient relationship and health outcomes; on the other, it has given rise to visions of timely, high quality, accessible, understandable, reliable and relevant information for patients and carers (Attfield *et al.*, 2006).

C.8 Understanding of the word 'information'

Participants' understanding of the word 'information' ultimately affected their responses. Most participants found it difficult to express this in words, with several people highlighting the complexities associated with the concept 'information'. For example:

"Well, it can mean different things depending on what you're talking about ..." (A14, line 8)

However, of those participants who were able to provide a definition, most viewed information solely in terms of the information that they received, as illustrated by the example below:

"Well, it's telling people about what things are about, isn't it?" (A6, line 5)

Others recognised the 'advice' facet of information; for example:

"Information ... erm ... guidance ... really ... err ... and advice ... on anything." (B6, lines 68)

A few participants emphasised the two-way flow of information:

"Well, information ... is ... err ... getting communication, more than anything else, I suppose, communication between those who are providing a service and those who are wanting a service ..." (A17, lines 74-76)

These definitions of information are in line with the dictionary definition presented in Section 2.4, that is, participants clearly viewed the term 'information' as a process (informing), or a kind of message.

It was clear that most participants had a good awareness of the wide range of information sources and formats available:

"Erm ... it means organisations, bodies, trying to put over what services they might have. It might be err ... on the street ... it might be on radio, TV, through the media. It might be written ... it might be email." (B10, lines 48-50)

However, most participants found it difficult to explain their understanding of the phrase 'health and social care information'. A few people pointed out that this meant different things to different people; for example:

"I think it really depends on the individual person ... and what their particular needs are." (B10, lines 55-56)

Other participants thought that the definition of social care information provided in the study's information sheet needed to be expanded upon to include "... *the whole gamut of social interaction*" (A17, line 101-102)

C.9 Interaction with information providers

It emerged that participants' interactions (positive and negative) with the different information providers and their progression through the various different health and social care services affected their information behaviour. For example, as noted under Theme A, many participants commented on their dissatisfaction with the quantity and quality of information they had received, particularly from the ophthalmologist at the time of diagnosis. Several Group A participants described how they felt they had been spoken to in an inappropriate manner during their consultations with the ophthalmologist. This is illustrated by the following quote:

"... you see some of them talk down to elderly people ... and I think it's all wrong ... especially if you're sort of equipped upstairs, you know." (A2, lines 108-110)

Some participants elaborated on this and gave examples of how they felt they had been treated unfairly by the hospital staff, particularly that their appointments had been rushed:

"... I didn't actually see the consultant ... I saw one of his team ... and I said what does that mean ... and he was very officious ... he said 'Oh you'll see when you get there ... and no cheating'." (A2, lines 99-101)

It also emerged that several participants thought that the ophthalmologists had been unsympathetic towards their visual impairment and did not fully understand the psychological implications of being visually impaired. This is illustrated by the following example:

"... I think some of the doctors ... err ... they're very dismissive ... because ... err ... doctors may not think ... err ... they're important enough ... for immediate treating ... but ... err ... for us ... it's ... err ... uncomfortable ... and it could improve ... even if it's only marginally ..." (B3, lines 209, 215-218)

"One of the problems is that many of the people at the hospital avoid the issues altogether and just think that it will go away." (A12, lines 1185-1186)

Other participants questioned the communication skills of some health care professionals and suggested that they required training in this area:

"... they should be sent on some kind of course to teach them how to actually treat people ... and not to treat them as though they are illiterate or don't understand." (A12, lines 1183-1184)

These kinds of interactions could clearly affect a person's information behaviour. For example, these participants may either have chosen to end their consultation as quickly as possible in order to get out of a difficult situation, or they may have had to be persistent and ask repeated questions in order to obtain the information that they required. This is aptly demonstrated in the following quote from a Group B participant:

"... I've always had to ask them ... err ... because ... especially the current surgeon I'm under ... he ... err ... tends to ... err ... want to get the appointment over as quickly as possible ... err ... very dismissive ... so I have to ask the questions." (B3, lines 99-102)

Although it is acknowledged that ophthalmology departments have to manage increasing case loads, these issues are of particular concern because they suggest that only persistent people are actually being provided with the information that they need in order to make informed decisions about their visual impairment. An alternative approach could be to provide a 'drop-in' advice clinic at the hospital, possibly run in conjunction with the local society for the blind. This latter suggestion has in fact been adopted by a local society for the blind, as described in further detail in Section 7.4.5.

Theme D. 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; these are shown in Figure 6. However, it is noteworthy that a few participants stated that they were completely satisfied with the information and help that they had received and were unable to suggest any improvements. For some participants the solution was simply to provide more, in particular up to date, information:

"By giving them information ... it's just not there!" (A5, line 590)

"... my personal need ... as I've just said is for up to date information ..."
(A12, lines 968-969)

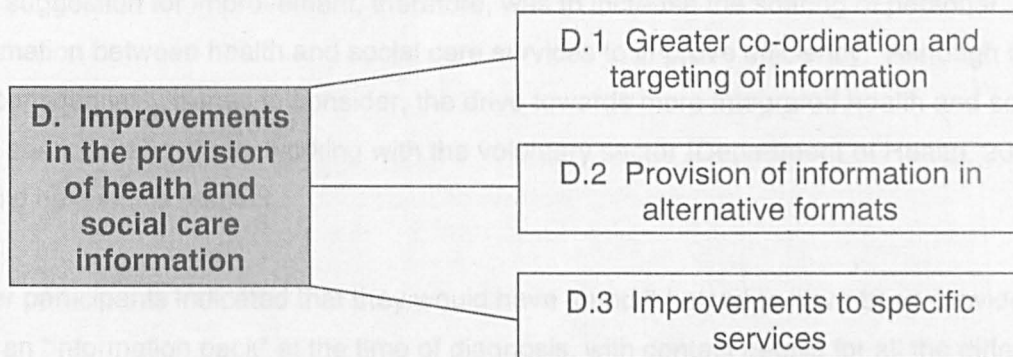


Figure 6. The interview sub-themes of Theme D 'Improvements in the provision of health and social care information'.

D.1 Greater co-ordination and targeting of 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. This was also evident from the variety of information sources participants used, as highlighted in under Theme B. Several other authors (e.g., Ahmed *et al.*, 2001; RNIB, 2001c), have also identified that a more co-ordinated approach to information provision is required. It is evident from the literature (e.g., Young, 2006) that this is part of a broader issue relating to service fragmentation and duplication between the NHS, local authorities and voluntary organisations.

One major concern expressed by participants was the need for visually impaired people to provide the same information, usually personal details, to each service independently, rather than for this information to be automatically shared between, and even within, organizations. On the whole, participants would have preferred to have been asked at the time of diagnosis whether they were happy for their personal details to be shared with different agencies, rather than having to repeatedly give out the same information. This is illustrated by the following quote:

"Each time I've been at hospital, they've asked me ... questions ... for the form ... you know a standard set of questions ..." (A11, lines 62-63)

One suggestion for improvement, therefore, was to increase the sharing of personal information between health and social care services to improve efficiency. Although there are confidentiality issues to consider, the drive towards more integrated health and social care services, and closer working with the voluntary sector (Department of Health, 2006b), should help in this respect.

Other participants indicated that they would have found it helpful to have been provided with an "information pack" at the time of diagnosis, with contact details for all the different health and social care services

"... to have a pack which told me what was available." (B10, lines 57-58)

"... some sort of protocol that could ... sort of ... link ... erm ... the full ... services together ... of ... erm ... people that are all dealing with different ... visually impaired ... erm ... societies ... and social side ... health care ..." (B14, lines 199-202)

A few participants favoured the idea of having a national telephone helpline for visually impaired people, as illustrated by the following quote:

"... I think we need a ... erm ... special sort of helpline number ... there could be some sort of call centre just for visually impaired people ... whereby they can call ... and ... erm ... basically access whatever information they need ..." (B6, lines 181-182, 184-187)

This appears, however, to contradict the earlier finding of participants' limited awareness and use of NHS Direct.

On the other hand, some participants thought that more information about eye conditions and visual impairment services should be provided at local GP practices and libraries:

"I think ... maybe ... erm ... GPs ... you know ... could help to ... distribute information as well ..." (B13, lines 203-204)

"... so possibly through agencies attached to information you can get from your local library." (A2, lines 381-382)

Finally, it was clear that participants felt that the information provided to visually impaired people needed to be targeted more to their specific needs. For example, many participants commented on their frustration about being sent information either in an

inappropriate format or about irrelevant eye conditions. This is illustrated by the following quote from one of the Group B participants:

"so perhaps ... you know ... if ... my medical records ... show whatever condition I have ... then ... err ... you know ... maybe ... the health service should ... be proactive in sending targeted information to ... err ... into constituents ... you know ... if there is a Nystagmus Weekly ... or whatever ... it should be perhaps ... ensure that ... I am aware of it ... and ... err ... perhaps even send it." (B9, lines 255-259)

D.2 Provision of information in alternative formats

Many participants also wanted information to be provided in a person's preferred format as a matter of course, rather than visually impaired people having to ask explicitly for this.

For example:

"... I think ... a wider range of formats should be available ... i.e., large print, audio cassette ... Internet ... mind you, you can't really send letters on Internet ... but ... maybe emails ... floppy disks ... erm ... Braille ... err ... just a wider range so that people have got more choice ... erm ... instead of having a standard print letter that nobody can read." (B2, lines 151-155)

Participants wanted a variety of media (e.g., verbal and written) to be used depending on the nature of their visual impairment and on the information being conveyed. This builds on the comments made about people's preferred format for information under Theme A. In addition, a few participants suggested that IT should be used more. However, the limitations of this method were also acknowledged:

"Mmm ... I think a lot ... a lot more use of multimedia ... but we have to think of the older person who's not maybe familiar with the multimedia, I suppose ... you know ... if you're thinking of the whole community." (B10, lines 322-324)

In line with other research in the field (e.g., Beverley *et al.*, 2004), it was clear that information, regardless of the purpose, must be provided in alternative formats more readily. Only a few participants, all people with a visual impairment since birth or early childhood, believed that health and social care information should be provided in Braille as a matter of course. For most participants, providing information on tape or large print was sufficient. A few participants expressed a preference for receiving information via email.

D.3 Improvements to specific services

Some participants also went on to suggest improvements to a variety of different services, ranging from public transport to notices in shops and restaurants. Suggestions included providing travel information on a CD for visually impaired people, for example:

"They have ... in the bus station ... a central database ... for ... for doing this, so why can't they very simply mount it on CD and send it out to us?"
(B10, lines 402-404)

The majority of the other suggestions from participants, particularly those from Group A, did not specifically relate to information needs and concerned improving access to sighted helpers to aid participants with everyday activities, such as shopping and cleaning.

Finally, it is noteworthy that several participants indicated that they were pleased that this research study was being conducted and enjoyed being interviewed, as illustrated by the following quote:

"And it's only through people like you that they are aware of these things."
(A2, lines 369-370)

4.4.7 Research limitations

It should be noted that 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), but instead tries to ensure that the findings are transferable to similar groups. For practical reasons, a convenient 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 reasons for people deciding whether or not to take part were not explored; however, this would be interesting to investigate further. The interviews with the three visually impaired couples produced very 'rich' data. However, it is possible that by interviewing members of the couples together this biased the findings and prevented individuals from expressing their personal opinions. It should be noted that the interviewing of couples together was done at the specific request of the participants, rather than as part of the original research method.

The majority of participants were white-British; had had a visual impairment for more than twelve months and were registered either blind or partially sighted and were, therefore, already in contact with relevant services. However, previous studies have found that only one-third of visually impaired people are formally registered as being blind or partially sighted (Robinson *et al.* 1994; Bunce *et al.* 1998). The proportion of participants with other health conditions and disabilities was, however, in line with previous research (Bruce *et al.*, 1991). 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. For example, in general the participants in Group B were younger, more active and had fewer additional health conditions.

In terms of dependability, although another researcher undertaking the same study is likely to come to similar conclusions, it is possible that they would analyse the data in a slightly different way (*i.e.*, identify different themes, depending on their research perspective and personal background). Only one person analysed all of the interview transcripts. Ideally this step should be performed by two people independently. Three of the advisors to the research study were, however, actively involved in informing the analysis framework and this was discussed in-depth with the academic supervisor.

Finally, it is difficult for any researcher undertaking qualitative research to remain completely impartial. Inevitably the researcher's pre-conceived ideas will have influenced the topic guide and the manner in which the questions were asked. Similarly the social interaction between the researcher and the interviewees will have affected the 'richness' of the data obtained from each interview. Attempts were made to address this, however, by piloting the topic guide with two of the advisors to the study.

4.5 Conclusions and Implications

To conclude, this qualitative study 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, 2002a) by identifying how and where visually impaired people obtain health and social care information, as well as by highlighting their unmet

information needs. In general terms there appears to be a wealth of information about health and social care matters available to visually impaired people. However, this information is not always readily available and/or accessible to people with visual impairments. In order to derive meaningful conclusions from this study, it is helpful to return to the original research questions.

4.5.1 What are the major health and social care information needs of people with a visual impairment?

On the whole, participants' health and social care information needs extend the findings of Beverley *et al.* (2004) and mirror the eight 'clusters' identified by Moore (2000). People with a visual impairment are, therefore, likely to require information on the following types of health and social care matters:

1. The eye condition, in particular information about the diagnosis, prognosis, treatment options, and its causes.
2. Health and social care services and facilities, including reading general correspondence and assistance with filling forms in.
3. Aids, adaptations and equipment, such as visual aids (*e.g.*, magnifiers); handrails; talking books; talking watches; liquid level indicators, *etc.*
4. General health care, including techniques for administering medications, such as eye drops and tablets; reading medical information, such as appointment letters, prescriptions, medicine labels, hospital notices and signs, *etc.*
5. Benefits and money, including knowing about the financial benefits available to visually impaired people; recognising different coins and note; and using cash machines.
6. Mobility, including using public transport, shopping, eating out, going on holiday, *etc.*
7. Housing and accommodation, including performing household chores, such as cooking and cleaning.
8. Employment, education and training.

The format, timing, quality and quantity of information are in some cases hindering a visually impaired person's ability to access accurate and up to date information. For example, much of the information is provided verbally at the time of diagnosis when the person may still be in a state of shock and is unable to 'digest' the information being given. It is clear that only some of visually impaired people's information needs are currently

being met automatically by the information that they receive, as illustrated by the participants in this study relying on additional information that they acquired and/or sought from other sources, as well as the large numbers of unmet information needs identified.

4.5.2 What information sources do people with a visual impairment use to obtain information about health and social care matters?

People with a visual impairment use a wide range of information sources in order to obtain the information they need about health and social care matters. This includes health and social care professionals, societies, organisations and support groups, friends and family, the mass media, and the Internet. In this study, health care professionals and the local society for the blind emerged as the major information providers. However, there was clearly considerable duplication of information across different organisations, particularly between Social Services and the local society for the blind, which resulted in some confusion amongst visually impaired people about the most appropriate source.

4.5.3 What factors affect the health and social care information behaviour of people with a visual impairment?

This research has demonstrated that the type, length and registration 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 within each of the two groups interviewed, particularly within Group B. These differences are similar to the barriers and facilitators identified in the Beverley *et al.* (2004) review. It is difficult to draw definite conclusions based on these other variables because of the small sample sizes involved. However, it is likely that factors, such as the presence of other health conditions and/or disabilities; the degree of independence exhibited by individuals; the quantity and quality of support received from friends and family; individuals' acceptance of their visual impairment; their willingness and ability to pay for aids, adaptations and equipment; the extent to which an individual can be regarded as an "expert patient"; their understanding of the word 'information'; and peoples' interactions with information providers will ultimately affect visually impaired people's health and social care information needs. For example, people with other health conditions and/or 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 identify factors, such as age, gender, and ethnic origin, may influence visually impaired people's information needs. These factors were not specifically addressed in this study, but Higginbottom *et al.* (2006) has recently investigated the specific needs of Somali visually impaired people. They found that this group of people faced an additional barrier of information only being provided in English.

4.5.4 To what extent can current developments in information provisions (e.g., NHS Direct and the Internet) help to meet the health and social care information needs of people with a visual impairment?

Newer sources of information, in particular NHS Direct and the Internet, have the potential to improve access to health and social care information to visually impaired people. However, these sources are still relatively recent sources and various barriers (*e.g.*, availability and cost of specialist accessibility software) must be overcome before they can be considered a viable addition to existing information sources. The low level of awareness of NHS Direct amongst participants in this study suggests that this service needs to be promoted more actively to people with visual impairments. It is possible that people's perceptions and awareness of NHS Direct may have changed since this study was conducted in 2003-2004, however.

4.5.5 Implications for practice and future research

This study has identified a few implications for practice, including the need to provide health and social care information automatically in a person's preferred format; to coordinate and rationalise the information provided by different organisations; to promote newer information sources, such as NHS Direct and the Internet, more actively to visually impaired people; and to engage visually impaired people in designing services, particularly in terms of identifying the most appropriate time for information to be provided by health and social care professionals.

The study has also highlighted various areas requiring further research. In particular, in response to identifying local societies for the blind and partially sighted as a major information source on health and social care matters, it would be interesting to explore further the role of societies, organisations and support groups in meeting participants'

information needs. It would also be useful to address the concern of duplicating work between different agencies by investigating the barriers and facilitators to providing an integrated information service for visually impaired people across the NHS, social care and voluntary sectors. These issues are explored further in Chapter 6 of this thesis. This study has also confirmed that future research should recognise visually impaired people as a heterogeneous group and, where possible, people with visual impairments should be actively involved in designing and conducting research in this field; this is explored further in Chapter 7.

CHAPTER 5. AUDIO DIARY STUDY

5.1 Introduction

Some traditional data collection methods (*e.g.*, questionnaires) do not lend themselves well to research with visually impaired people. For example, self-administered questionnaires, either paper or electronic, are not generally accessible to visually impaired people. Although alternative formats can be provided, no single format will meet the needs of all visually impaired people; for example, some people will prefer large print, some Braille, whilst others will express a preference for spoken word. Individual face-to-face interviews, as utilised in Chapter 4, are an effective way of obtaining the views and experiences of visually impaired people at a particular point in time, but they are dependent on the retrospective recall of information. When studying information needs and behaviours, it is important to also collect data over a longer period of time so that issues of information timing, frequency and processing can be explored. For these reasons, a longer-term audio diary study with a small number of older visually impaired people was undertaken to supplement the interview study.

The audio diary methodology was introduced in Section 3.4.2. Audio diaries, where key events, experiences and thoughts are recorded by participants, have the ability to capture behaviours as they occur. Since audio diaries have not been used commonly either in the field of information behaviour or with visually impaired people, the researcher thought that this was an ideal opportunity to evaluate this approach in studying the health and social care information needs of older people with a visual impairment. Papadopoulos and Scanlon's (2002b) successful pilot audio diary study of the health and social care welfare needs of three visually impaired people indicated that audio diaries had the potential to be used with visually impaired people. The study described here addresses some of the limitations of the Papadopoulos and Scanlon (2002b) study, in particular, that the diaries were only made during the course of a single day and that the diaries were largely unstructured.

This chapter describes in detail the methods used and discusses the results within the context of the framework identified in Section 4.4.6. However, the emphasis of this

chapter is on evaluating the use of the audio diary method with older visually impaired people, both from the perspective of the participants and of the researcher.

5.2 Aims and Research Questions

The main question which this part of the research was designed to answer was:

1. What are the strengths and weaknesses of using audio diaries as a research method with older visually impaired people?

In addition, it was hoped that the findings would supplement the interview study in answering the overarching research questions of the thesis, as presented in Section 2.7.

5.3 Methods

5.3.1 Study design

In accordance with the conceptual framework of this research introduced in Section 3.2, the audio diary study followed a constructivist approach (Patton, 2002). The research was, therefore, qualitative in nature and comprised:

1. Individual semi-structured face-to-face interviews with a small sample of older people with a visual impairment prior to participants making their audio diary.
2. Audio diaries with a small sample of visually impaired people.
3. Follow-up individual semi-structured face-to-face interviews with these diarists.

The initial individual semi-structured interviews with participants enabled the researcher to explain the purpose of the research and helped participants to start to explore their information needs and behaviours. In addition, the researcher was able to demonstrate the equipment to be used for making the audio diaries and the participants were able to ask any questions they had about the study. The audio diaries were made by the participants independently from the researcher. The follow-up interviews with participants allowed the researcher to clarify any issues raised by the participants in their diaries.

5.3.2 Sampling and recruitment

It was hoped that approximately five people would take part in this study. Participants were originally recruited via a local hospital low vision clinic. This recruitment route was chosen because most people attending this clinic would have recently received a diagnosis of a visual impairment and so were likely to have various information needs relating to their health and social care. The health care professional (*e.g.*, orthoptic nurse) managing the clinic was responsible for informing the clients of the research study, providing them with an information sheet (see Section 5.3.3), and seeking permission to pass on their contact details to the researcher if they were interested in participating. Unfortunately, due to problems in recruitment (see Section 5.4.1), alternative approaches had to be used. This involved attending a local society for the blind and partially sighted consultative forum, and putting an advert in the Macular Disease Society newsletter.

5.3.3 Procedure and materials

Once a person had agreed to take part, they were contacted by the researcher to arrange a face-to-face semi-structured interview. The participants were given the choice of venue for the interview (in their own home, at the University, or at a neutral venue, such as the local society for the blind). At this point, the participants were sent an information sheet outlining the study in more detail, shown in Appendix E, and guidance notes on how to make an audio diary, shown in Appendix F. Both of these were provided in the participants' preferred format (*e.g.*, large print, audio tape or email). At the start of the interview, the participants were asked to consent verbally to take part in the study. Verbal consent was considered more meaningful than written consent in this case. This was because the researcher was able to explain the purpose of the study in person, rather than rely on the participant signing a consent form that they were unable to read because of their visual impairment. The same interview topic guide was used as for the main interview study (refer to Appendix D). The interviews were tape-recorded, with permission from the interviewee.

At the end of the interview, each participant was issued with a tape recorder (a *Sanyo Talk-Book VAS Compact Cassette Recorder TRC-1148*) and a cassette. Instructions on how to use the tape recorder were provided verbally by the researcher. The participants were encouraged to make their first diary entry in the presence of the lead researcher.

Participants were asked to start their diary by clearly stating their name and giving a brief background to themselves and their visual impairment. Although the diaries aimed to be fairly unstructured, participants were requested to state the date and time before making an entry. To help participants to remember to make an entry, they were asked to record something for each day, even if this was simply to state, “*nothing to report*”. Participants were asked to make a ‘live recording’, rather than a retrospective account, of any issues that arose concerning their health and social care information behaviours during the following four weeks.

The researcher contacted the participants on a weekly basis to check progress with the diaries and to enable the participants to ask any questions they may have had. The researcher returned to the participant’s home to collect the audio tape and tape recorder at the end of the four weeks. Within one month of the audio diary data collection period, the participants were interviewed again to clarify diary entries and to explore the participants’ views of the research approach; a copy of the interview topic guide is provided in Appendix G.

5.3.4 Analysis

The interviews and audio diaries were transcribed in *Microsoft® Word 2002* within four weeks of the data collection period. Both the initial and follow-up interviews and audio diaries were analysed using framework analysis (Ritchie and Spencer, 1994), as advocated by Jones (2000). The framework emerging from the interview study, as described in Section 4.4.6, was used to analyse the findings from the initial interviews with participants.

5.3.5 Trustworthiness

By adopting a “diary-interview” method (Zimmerman and Wieder, 1977), whereby the people recording the audio diaries were subsequently interviewed, the internal consistency of the participants’ accounts could be checked (Elliott, 1997) in order to maximise intra-observer reliability and increase confirmability. In addition, as diaries are generally less affected by recall bias (Bowling, 2002), they have the potential to provide a valuable check

on the reliability of the data collected retrospectively via the interview study. This is elaborated upon in Chapter 8.

5.3.6 Ethical approval

NHS Local Research Ethics Committee approval was obtained from the South Sheffield Research Ethics Committee to undertake this pilot audio diary study in June/July 2003.

5.4 Findings

5.4.1 Number of participants

In total, seven people successfully made an audio diary between September 2003 and April 2006. Two of these people were recruited via the local low vision clinic in Sheffield, three people were recruited in Cumbria as a result of an advert in the Macular Disease Society newsletter and two people were recruited as a result of attending a local society for the blind and partially sighted consultative forum in Cumbria.

5.4.2 Participant characteristics

Five of the participants were women and two were men. Their median age was 71 years, with a range of 60 to 81 years of age. All the participants were White-British. Six participants lived alone, whilst one lived with a spouse. Six participants had age-related macular degeneration (AMD), whilst one had diabetic retinopathy. Five participants were registered either as sight impaired or severely sighted impaired. Finally, five participants had other health conditions and/or disabilities, in particular asthma, arthritis and mobility problems.

5.4.3 Length and duration of the audio diaries and follow-up interviews

The median duration of the audio diaries was 33 minutes, with a range of 10 to 51 minutes, and a median word count of 4,778 words. The median length of the follow-up interviews with participants was 21 minutes, with a range of 10 to 43 minutes.

5.4.4 Previous diary experience of participants

All seven participants had kept some kind of written diary in the past, either for appointments or personal purposes. However, none had made an audio diary before and the experience was, therefore, new to them.

5.4.5 Format of audio diaries

Participants adopted various approaches to making the audio diary. On the whole, the diaries were semi-structured, with the date and time being stated at the start of each entry. However, the majority of entries were retrospective, *i.e.*, recorded after an event had occurred, rather than the 'real life' recordings that were originally envisaged (Bowling, 2002). The diary of one participant was less structured and followed the format of a personal diary which captured specific life experiences and thoughts.

5.4.6 Key audio diary themes

The audio diaries themselves were analysed using the framework which originated from the interview study, as described in Section 4.4.6. The emphasis in this section is, therefore, on identifying the major similarities and differences in the themes emerging from the audio diaries compared to those previously identified.

Before looking in more detail at each of the themes, it is useful to note some general observations about these findings. The focus of all the diaries was on experiences that the participants encountered, either as part of the data collection period, or from previous events which participants recalled for the purpose of the diary. There were very few diary entries which specifically referred to "health and social care information": the researcher, therefore, had to extract this information from the transcripts. What is particularly interesting about these findings is how the diaries provide some context and deeper meaning and understanding to the interview study findings, in particular by elaborating on the "intervening variables" identified in the interview study.

All the quotes provided below originate from the audio diaries, rather than either the initial or follow-up interviews.

A. Health and social care information needs

Interestingly, the audio diary participants referred to all of the different types of information identified in the interview study, with the exception of information about eye conditions, and information about employment, education and training. The latter is not particularly surprising since all the participants were retired and, therefore, their need for information about employment, education and training was less than for visually impaired people of working age. Since most participants had had a visual impairment for several years, it is also possible that their need for specific information about their eye condition was less, that is, they had already received a diagnosis and prognosis and were aware of the treatment options that were available. If a new treatment had become available during the data collection period, then it is possible that participants would have recorded something about this on the diary. Similarly, newly diagnosed visually impaired people would probably have been more likely to discuss their information needs relating to their eye conditions.

In terms of information about health and social care services and facilities, most of the participants' diary entries on this matter related to the difficulties participants faced in reading general correspondence, and how they depended on equipment (*e.g.*, Closed Circuit Televisions, CCTVs), family, or carers to help in this respect. This is illustrated by the following quote:

"Erm ... then at 1 o'clock my support worker came to go through my post and we sorted all that out and we got it all up to date, filed away and everything." (Audio diarist 7, lines 42-43)

All the participants referred in their audio diaries to the aids, adaptations and equipment that they either used or were aware of, such as CCTV, magnifying glasses, large print telephones, talking books, talking watches, talking weighing scales, liquid level indicators, symbol canes, coloured bump-ons for washing machines, computers, cookers, *etc.* For example:

"In order to see the dials on the machine ... I had to get my magnifying glass ..." (Audio diarist 5, lines 54-55)

"... on my washing I have coloured bump-ons ... orange bump-ons ... and they're a great help ..." (Audio diarist 6, lines 51-52)

"I get great pleasure from reading talking books." (Audio diarist 7, line 51)

However, very few participants alluded to any information needs relating to these, perhaps because they already owned them or knew where to get them from. One participant, who attended a new pilot low vision clinic at the local society for the blind while making her diary, discovered that the low vision aid that she was currently using was not the most appropriate:

"but the expert you might say ... on the provision of low vision aids ... we talked ... I showed him the equipment that I had and he actually said that the one that I had been given by the clinic ... was oversubscribed so he gave me a lower strength one, which to be quite honest, is actually much better." (Audio diarist 6, lines 149-153)

Interestingly, several participants, despite indicating their knowledge of different aids, adaptations and equipment, also showed their determination not to get them. For example:

"I know I can get one of these gadgets that bleeps when you've filled it to a certain height but ... err ... I'm very loathed to do so ... I prefer to try myself. Maybe one day ... I will succumb to getting them." (Audio diarist 5, lines 92-94)

Some participants, mainly those who had other health conditions, also referred to general health care information, in particular their strategies for identifying tablets. This is illustrated by the following quote:

"And earlier on I was getting frustrated ... I have to take ... err ... 3 tablets ... medication in the morning ... you know ... and 4 tablets in the evening ... I keep the ones for the morning upstairs ... and the ones for the evening downstairs ... but ... err ... it's very difficult to tell ... err ... what all the tablets are. And I can't manage to do so ... without the help of my CCTV ... so thank goodness I've got that." (Audio diarist 4, lines 20-25)

This example also highlights the importance of aids, adaptations and equipment.

A few participants referred to the difficulties they faced in terms of benefits and money, such as problems in paying for goods and services as a result of not being able to see where to sign and/or enter a PIN number. The person who attended the pilot low vision clinic at the local society also reported information needs relating to benefits available to older visually impaired people. However, as can be seen from the quote below, she was already aware of this information:

"Talked about the ... err ... benefits ... would I like to talk about the financial benefits that were available ... which I do actually know about because of my involvement in the society." (Audio diarist 6, lines 145-147)

Issues concerning mobility were raised by several participants, particularly in relation to crossing roads, using public transport, shopping, and going on holiday. Again, very few, if any, information needs were identified. Although most of the comments related to difficulties, examples of good practice were provided, such as the use of the disabled passenger facility on inter-city trains:

"Wonderful service ... someone came along ... put me on the train and into my seat." (Audio diarist 6, lines 450-451)

Finally in terms of the type of information, most participants referred to the difficulties and frustrations they encountered on a daily basis with regard to their housing and accommodation, in particular cooking and cleaning, as illustrated by the following quote:

"I've just spent half the morning trying to work out the controls of the ... gadgets on my new vacuum ... it takes me twice as long as it should because I have to ... err ... keep going to the CCTV to read the instructions ... and then feeling the spaces and knobs on the vacuum. Very frustrating!" (Audio diarist 5, lines 10-13)

Perhaps the most prevalent diary entry related to the format of information, in particular participants' frustrations about the continued use of inaccessible print:

"Oh ... to start off it was very frustrating going through the catalogue ... finding ... all the instructions and numbers ..." (Audio diarist 4, lines 363-364)

"... because the times of the train ... are written on the ticket but in little dots and it makes it very very difficult to ... err ... read." (Audio diarist 6, lines 237-238)

"... attempted to read some of my travel instructions for Australia ... from the travel company ... extremely difficult to read ... and at times impossible ... because mainly on the very faint print ... and occasionally because of the coloured background." (Audio diarist 2, lines 30-33)

However, it was also clear that participants appreciated when service providers made an effort and provided information (e.g., bank statements, letters, etc.) in alternative formats:

"I'm very thankful that the bank sent me a statement in large print which makes it a bit easier." (Audio diarist 5, lines 302-303)

"Very well produced leaflet ... with ... erm ... large print ... very clear instructions and information." (Audio diarist 6, lines 25-26)

The above examples illustrate the usefulness of the audio diaries in highlighting difficulties participants experienced in their day-to-day lives, and reflect the findings of other authors, such as Bruce *et al.* (1991), who found that the majority of visually impaired people experienced problems with at least one aspect of daily living skills, such as personal care and domestic tasks.

Only one participant specifically referred to the timing of information and that was the person who attended the pilot low vision service at the local society for the blind. She felt that this new service had the potential to provide visually impaired people, particularly newly diagnosed people, with all the major pieces of information that they needed all at the same time in the same place:

"... it was a one stop shop where you could see somebody from Social Services ... and ... be introduced to the ... the people at .. [the local society for the blind] ... and have a look at the equipment we have in addition to ... the most important thing ... seeing an expert ..." (Audio diarist 6, lines 175-179)

Little reference was made in the diaries to the quantity and quality of information received, although one participant did state that:

"... the more clutter ... the more confused I get ..." (Audio diarist 6, lines 223-224)

This suggests that information may be more positively received if it is targeted at specific groups of people and provided in more manageable amounts.

B. Sources of health and social care information

Unlike the interview study in which the major source of information about health and social care matters was health care professionals, the major information sources for the audio diary participants were societies, organisations and support groups, and friends and family. This difference can probably be explained by the fact that, in general, the audio diary participants were not actively seeking information about their health and social care, but instead acquired information via various routes. It is, therefore, somewhat surprising

the neither the mass media (e.g., television, newspapers, magazines, etc.), nor the Internet were referred to at all in any of the diaries. This could be because during the data collection period, there were no noteworthy news stories about visual impairment. This is unlikely, however, given that the audio diaries were completed over a large time period (from September 2003 and April 2006) and each participant kept a diary for four weeks. It, therefore, suggests that the people taking part in this study did not think that the news stories warranted mention in the diary, either because they felt it fell outside the scope of the research, or because they had already dismissed the claims behind the news story. It would be interesting to explore this issue further. With regard to the lack of mention of the Internet as a source of information, this could be related to the age of the participants, particularly as only one participant even mentioned using a computer. It could also be due to the lack of access to a computer and/or computer training.

As noted above, local and national societies, organisations and support groups were a major source of information for the audio diary participants, as illustrated by the following diary entry:

"... this morning we had a meeting of the Macular Disease Support Group at my house with twelve people attending ... err ... we had a general discussion on the difficulties we have with ... err ... obtaining suitable advice." (Audio diarist 5, lines 15-17)

This participant went on to say how the meetings were a good opportunity to exchange information and learn from each other:

"... but all in all it was a good exchange of information ... and ... erm ... I hope people will be able to contact the right people in future." (Audio diarist 5, lines 33-35)

The local society for the blind also clearly emerged as a major source of information, as illustrated by the following diary entry:

"another volunteer worker at the blind society who is very very good ... she's very knowledgeable ... she's the person who helps people to get grants to buy expensive equipment ..." (Audio diarist 6, lines 354-357)

In addition to being a key information source, local and national societies, organisations and support groups also provided valuable social contacts and networks. For example, the reference to "club" in the following diary entry suggests this:

"and I went to the partially blind ... partially sighted and blind club ..." (Audio diarist 4, lines 201-202)

Friends and family were also a very important source of information and support to the audio diary participants. This ranged from them reading correspondence to helping with daily activities, such as cooking and cleaning. The following quotes illustrate this:

"And I also have another good friend ... who has always done my reading for me ... she is completely trustworthy and I would ... err ... share anything with her ... she had filled in forms for me about benefits and things like that." (Audio diarist 6, lines 334-336)

"err ... bus timetable has changed and my route to the buses. However, I got one of my friends to sort it out for me ..." (Audio diarist 6, lines 503-504)

"... my wife, spent most of the morning ... err ... putting some stick-ons onto the computer ..." (Audio diarist 3, lines 265-266)

The first of the above examples also highlights the potential vulnerability of visually impaired people. For example, people with visual impairments often have to depend on friends and family to read all their correspondence for them, including personal and sensitive information, indicating that they had to trust the honesty and integrity of friends and family members.

Finally, friends were often a source of recommendations for aids, adaptations and equipment, as well as strategies for dealing with certain situations:

"Erm ... people have recommended talking scales to me ..." (Audio diarist 5, lines 231-233)

Other sources of information referred to by participants included health and social care professionals, such as GPs, practice nurses, opticians, ophthalmologists, social workers and rehabilitation officers. In terms of health care professionals, one participant described a visit to the optician for an annual diabetic eye examination and was relieved to learn that her condition had not deteriorated:

"Erm ... after the initial testing ... atrophy and drops were inserted into the eyes and I had 20 minutes to wait until the pupils were sufficiently dilated for the rest of the examination ... err ... I was glad to be told things haven't changed much since last year." (Audio diarist 5, lines 74-77)

Several other participants visited their general practice and/or hospital for health conditions unrelated to their visual impairment, such as for blood pressure monitoring. One participant found the system for administering repeat prescriptions particularly helpful to him:

"I had to pick up a prescription from the ... err ... and deliver it to the chemist ... erm ... which went well. I think one of the beauties is that I now pick up that prescription that's given to me ... me that's just phoned in ... err ... you know ... which is ... err ... pretty good ... and ... err .. and then, you know, ... across to the chemist ... I don't even have to sign it ... tick it ... or anything ... so ... err ... that's terribly helpful." (Audio diarist 3, lines 292-300)

C. Factors affecting information behaviour

The majority of diary entries related to the various factors affecting information behaviour identified in the interview study, and gave a greater insight into the lives of older visually impaired people. All of the factors previously identified were evident in the audio diary transcripts, either directly or indirectly. For example, participants' different understandings of the word 'information' emerged indirectly from the diaries. The most frequently cited factors in the diaries were the participants' degree of independence, the support they received from friends and family, and participants' personal acceptance and awareness of their visual impairment.

In general, the audio diary participants were very independent people, perhaps because the majority lived alone. In some cases, although participants knew that they only had to ask for help, they chose not to do so and tried to work the problem out themselves first:

"... it's just a case of asking ... but I always have a good try myself first before I accost anybody." (Audio diarist 5, lines 48-49)

Interestingly, one of the participants reflected on how initially she thought she was disadvantaged living alone, but how she was now relieved that she had not become dependent on someone:

"when I first ... err ... became affected my macular degeneration in both eyes ... I wished very much I had somebody living with me because it would really solve the problems by about 80% ... but as time went by, I began to realise that if that was so ... I wouldn't ... I wouldn't to solve ... or try and solve my problems myself ... so ... 'cos as you get older you can lose the

person living with you and then it would be doubly difficult, so I think that things have worked out ok ..." (Audio diarist 4, lines 428-434)

However, it was evident that several participants felt that, as a result of their visual impairment, they were losing her independence and were feeling more vulnerable:

"... well, I used to be quite independent, but now I seem to be going into myself." (Audio diarist 1, lines 80-81)

"Walked down into [town] ... sounds horrendous, doesn't it? Only takes about 20 minutes, but for part of the way ... the ... the ... err ... pavement is missing ... bit of a narrow road and ... err ... you do feel a bit vulnerable on that stretch." (Audio diarist 3, lines 88-91)

The importance of friends and family to the audio diary participants, particularly in terms of offering social support and avoiding feelings of isolation, was clear. This is illustrated by the following quotes:

"I've just made and received many phone calls which is very nice ... when friends and family phone." (Audio diarist 6, lines 54-55)

"... and we realise that some members [of the local support group] feel rather isolated when they don't have any visitors ..." (Audio diarist 5, lines 30-31)

This is reiterated by the following participant's comment about the lack of social interaction with her carers:

"The carers have been in a couple of times to see me, but no conversation whatsoever, apart from saying 'Are you alright?' ... and then they're gone." (Audio diarist 7, lines 86-88)

Most participants had evidently come to terms with their visual impairment over the years and generally had a positive outlook on life:

"Erm, however, I had to say at the beginning of this ... ailment, I would call it, of losing one's sight, that, err ... you have to say, it's not what I can't do, it's what I can do. So I'll plod on." (Audio diarist 1, lines 84-86)

"And ... always work on the principle that hopefully where there's a way there's a will! And it certainly does help!" (Audio diarist 4, lines 446-447)

On the whole, the audio diary participants had, therefore, reached the "acceptance" stage of adjusting to their sight loss (Crossland and Culham, 2000). This will undoubtedly have

affected a person's need for information, although it is not stated explicitly. For example, some visually impaired people may just accept their situation and chose not to seek out any more information, whereas other people may constantly strive to find answers to their questions.

Several participants commented on how things took them longer now as a result of their visual impairment and how it was important for them to remain patient:

"And one other thing I've learned is that ... I-I have to have patience with myself ... and I must always try not to rush and I must take my time ... and ... err ... just be patient." (Audio diarist 4, lines 442-444)

However, it was also clear that participants still became frustrated by certain situations:

"... I've just been getting frustrated trying to find ... err ... a telephone number I'd written down somewhere ..." (Audio diarist 4, lines 17-19)

"... but I feel at the moment that my life has gone a little bit flat and I'm not doing as much as I used to be doing ..." (Audio diarist 7, lines 165-167)

Other factors identified in the audio diaries included the presence of other health conditions, interactions with information providers, registration, willingness and ability to pay for aids, adaptations and equipment, and "the expert patient". As noted in Section 5.4.2, most of the participants had another health condition which meant that they were in more regular contact with health and social care services than other members of the public. The apparent link between back and shoulder problems and visually impaired people using a symbol cane also emerged in one of the diaries:

"Erm ... the physio, tells me that she has seen it many many times that people with impaired vision seem to have lower back problems ... because of ... especially those that use long ... particularly a long cane ... because we seem to hold ourselves more rigidly than would normally happen. Also she says that people very often have problems with their shoulder because of the movement ... because of moving it continuous with the cane, with the side to side ... erm ... movement." (Audio diarist 6, lines 75-81)

Participants' interactions with information providers also seemed to affect their information behaviour. For example, one participant ended up actively seeking information himself due to his frustration at the apparent lack of action by his local hospital in referring him to a specialist ophthalmologist regarding his eye condition:

"... they don't seem to be able to respond ... err ... unless you ... err ... actually push them ..." (Audio diarist 3, lines 162-163)

It was also evident that the exchange of information between different departments within the same organisations (e.g., banks, charities, etc.) was not always as good as it should be, so that not all information provided by a particular organisation was provided in the participants' preferred format:

"... my bank have been informed that I require all this material in large print. I do in fact receive my monthly bank statement in large print, but obviously not passed that across the various departments." (Audio diarist 6, lines 31-33)

The high cost of some low vision aids, adaptations and equipment, and the lack of availability on the NHS, was highlighted by some participants:

"... and I put off buying it because it was quite expensive ..." (Audio diarist 6, lines 347-348)

"... certainly down at the local hospital here ... in the low vision clinic ... err ... and you know they're reeling against giving people ... err ... £400 worth of ... err ... video magnifiers ..." (Audio diarist 3, lines 16-18)

Finally, it is worth noting that several of the audio diary participants could be regarded as "expert patients" which ultimately affected their information behaviour. For example, one participant ran her own support group, and was a key source of information and advice to other visually impaired people, particularly people recently diagnosed as having AMD. Another participant, as a result of her own difficulties in coming to terms with her visual impairment, now worked for a local society for the blind and also provided information and advice to others.

D. Improvements in the provision of health and social care information

The audio diary participants did not identify any specific improvements in the provision of health and social care information, probably because they were not explicitly asked to do so. However, from the audio diary transcripts, it was possible to identify areas where improvements were required and these generally reflected the themes identified in the interview study, *i.e.*, in terms of improving the co-ordination and targeting of information

(as illustrated by “... *the more clutter ... the more confused I get ...*” quote under Theme A), providing information in alternative formats, and improvements to specific services.

The majority of comments, however, related to improving the format of information on everyday items by using larger, clearer print or providing the information on tape. This is illustrated by the frequency of diary entries about the difficulties participants faced reading correspondence, labels, instructions, *etc.*:

“But ... perhaps the labelling of jars and things could be better for people with impaired vision.” (Audio diarist 6, lines 257-258)

Another participant who regularly encountered problems opening packages requested that manufacturers used raised coloured dots to help visually impaired people identify where to open items:

“... everything’s gone alright today, except I’ve had a couple of little problems opening a cereal packet and also a packet of biscuits ... and I thought how nice it would be if a lot of manufacturers could just ... err ... put an orange dot ... err ... at the best place to open whatever you’re trying to open ...” (Audio diarist 4, lines 160-164)

For another participant, who relied heavily on her telephone, both for information and social support, a key area for future development was the provision of free, or reduced rate, telephone charges for people with visual impairments:

“Erm ... if you want to push something for people who are disabled ... visually impaired ... how about starting a campaign for impaired ... people who need the telephone to communicate with the outside world for a reduction, or even the abolishing, of the standard charge for our telephones, so that then we only pay for our calls.” (Audio diarist 6, lines 65-69)

Therefore, to conclude this section, similar themes emerged from the audio diaries as from the interview study. The audio diaries provided additional insights into some of the themes, particularly the factors affecting visually impaired people’s information behavior. This is discussed in more detail in Chapter 8. The next section considers the use of audio diaries from a methodological perspective.

5.4.7 Audio diary methodology findings

The framework emerging from the follow-up interviews with participants was largely informed by the interview topic guide and is presented in Figure 7. Each of these themes is discussed in more detail below. Illustrative quotes from the second interview with participants are provided where appropriate, together with the corresponding line numbers from the relevant transcript.

A. Overall experiences of keeping an audio diary

In general, participants found keeping an audio diary a positive experience. This is illustrated by the following comments:

"Oh ... I liked it. I liked it." (Audio diarist 1, line 32)

"I thought it was a bit of fun really." (Audio diarist 4, line 37)

One participant who lived alone found that *"the diary was a friend"* (Audio diarist 1, line 35) and that it helped her to come to terms with going into respite care during the data collection period. This is a particularly interesting finding which warrants further investigation. For example, this raises the question whether offering audio diaries to all older visually impaired people whose circumstances change for whatever reason would help them to talk through their experiences on a tape. This would, of course, have to be supported by some form of support and/or advice service. Although it is acknowledged that direct human interaction would be preferable, audio diaries might provide a useful interim measure, especially given current resource constraints in the health, social care and voluntary sectors.

In contrast, another participant found making the audio diary *"sometimes a chore"* (Audio diarist 6, line 39). She went on to say that, although it was not an onerous task:

"... now I'm glad it's done! I don't want to start another one next week! [Laughs]." (Audio diarist 6, lines 42-43)

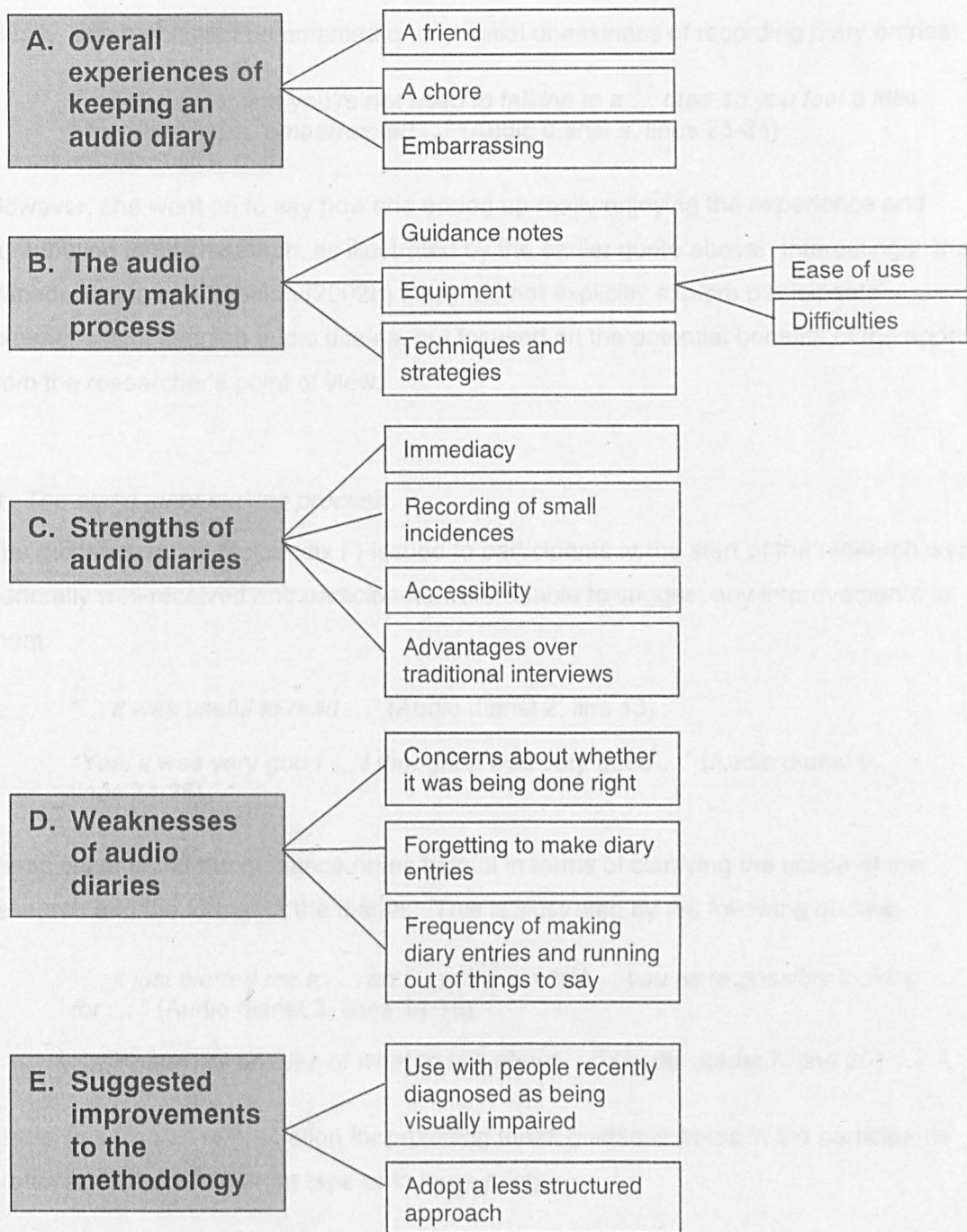


Figure 7. The framework emerging from the follow-up interviews with the audio diary study participants.

Finally, one participant commented on her initial uneasiness of recording diary entries:

"... because at first you're not used to talking to a ... tape so you feel a little bit ... [laughs] ... embarrassed ..." (Audio diarist 4, lines 23-24)

However, she went on to say how she ended up really enjoying the experience and contributing to this research, as illustrated by the earlier quote above. Interestingly, the Papadopoulos and Scanlon (2002b) study did not explicitly explore participants' experiences of keeping audio diaries, but focused on the potential benefits of the approach from the researcher's point of view.

B. The audio diary making process

The guidance notes (Appendix F) issued to participants at the start of the research were generally well-received and participants were unable to suggest any improvements to them.

"... it was useful to read ..." (Audio diarist 2, line 13)

"Yes, it was very good ... I thought it was very good ..." (Audio diarist 6, lines 34-35)

Participants found the guidance notes helpful in terms of clarifying the scope of the research and the format of the diaries. This is illustrated by the following quotes:

"... it just alerted me to ... err ... what ... what ... you were possibly looking for ..." (Audio diarist 3, lines 14-15)

"... it gave me an idea of what to talk about ..." (Audio diarist 7, line 20)

There was also an appreciation for providing these guidance notes in the participants' preferred formats (either on tape or in large print).

However, one participant appeared to find the sample diary entries in the guidance notes somewhat intimidating, and expressed concern as to whether she would be able to produce similar entries:

"I thought I must try to emulate that ... but I'm not sure I have!" (Audio diarist 6, lines 35-36)

In contrast, another participant found that the sample diary entries made her feel more confident:

"... gave me ... err ... confidence to know what to say ... you know ..."
(Audio diarist 4, lines 22-23)

Overall, participants found the tape recorder easy to use, as illustrated by the following comments:

"... that was quite easy actually." (Audio diarist 2, line 33)

"Oh, it was very straightforward." (Audio diarist 6, line 45)

However, one participant described the problems she initially had recording entries and how she had to wait for a carer to show her again:

"Oh ... I had a job getting used to the idea ... how to run it yes ... I know you explained it quite well ... I'd been trying to work it out ... I knew I had to click two buttons together and various combinations ... but eventually I got the hang of it ... so the actual first entry was done about 3 days after I started." (Audio diarist 7, lines 171-172, 175-177)

In addition, two participants alluded to potential problems, in particular their inability to rewind and reply items:

"I would have difficulty reversing it to go back to refresh my memory ..."
(Audio diarist 6, lines 63-64)

"I ... err ... never played anything back ..." (Audio diarist 2, line 334)

Participants demonstrated four main techniques and strategies for making their audio diaries. Firstly, several participants commented on putting their audio diary in an obvious place so that it reminded them to make entries:

"I left it here on the table so that I saw it and I thought, 'oh, my diary'."
(Audio diarist 6, lines 39-40)

Secondly, participants seemed to try and make diary entries at roughly the same time each day.

"... it was just myself ... getting me organised to say ... err ... well ... err ... at this point in time ... err ... during the day ... I'm going to say ... err ... this is what has happened ..." (Audio diarist 3, lines 36-39)

This is interesting because the researcher had advised participants to make entries as situations arose, rather than to record retrospective accounts. However, it emerged that although most participants did attempt to adopt this strategy, it was unfortunately rarely possible:

"I tried to do it immediately after some incident but sometimes I had to do it at night because there wasn't the opportunity." (Audio diarist 5, lines 32-34)

When undertaking studies like this it is, therefore, important to have realistic expectations and to allow participants to adopt an approach that meets their needs, rather than trying to impose a rigid structure upon them.

The third approach some participants adopted was to focus on issues that they themselves found problematic:

"I generally used to put in things that I tended to find a bit difficult ..." (Audio diarist 4, lines 38-39)

Finally, one participant preferred to adopt a story telling approach rather than a structured diary, as illustrated by the following quote:

"... I also found it easier to ... err ... do it ... the way ... I thought about ... in ... not so much a diary way ... but as a continual story ..." (Audio diarist 7, lines 21-22)

This is in line with the findings of the Papadopoulos and Scanlon (2002b) study, which found that audio diary studies *"allow the participants to tell their own stories without the restrictions usually associated with other methods used in research with people who are visually impaired"* (Papadopoulos and Scanlon, 2002b: 458).

C. Strengths of audio diaries

Four main strengths of audio diaries were identified by participants. The first of these was *"the immediacy"* (Audio diarist 3, line 49) and the fact that participants could record issues as they arose and when it was convenient to them. The second of these strengths was related to this and concerned participants being able to note *"small incidences"* (Audio diarist 5, line 39) which would otherwise have been forgotten. These two strengths are highlighted in the following quote from one of the participants:

"... because I think possibly ... especially when you get to my age ... your memory's not that good ... oh and you think, 'Oh I wished I'd remembered that ... and told you that' ... whereas I think doing it over a month ... things that crop up ... you know ... you record them." (Audio diarist 4, lines 53-56)

The third main strength identified was the accessibility of the method, in particular the ease of using the equipment and the benefits of recording diary entries on tape, rather than having to write them down:

"... if you'd said it was a written exercise ... I think if you were having to write it at the end of the day ... err ... it would be a real task." (Audio diarist 3, lines 49, 53-54)

Finally, it is interesting to note that several participants specifically commented on the advantages they thought audio diaries offered over traditional interviews; for example:

"... whereas in an interview ... you ... err ... forget ... some things that struck you at the time." (Audio diarist 5, lines 39-41)

"I think it's better doing it that way than having a one off chat." (Audio diarist 4, lines 56-57)

Papadopoulos and Scanlon (2002b) similarly identified several strengths of audio diaries, including that they offered insights that may be missed through other methods. In addition, they thought that diaries allowed the context of problems to be gleaned. This was certainly also the case in this audio diary study; for example, from the participants' descriptions it was possible to imagine some of the situations they faced during the data collection period, such as the difficulties participants experienced reading correspondence on a daily basis, and how frustrating this was for them. Papadopoulos and Scanlon (2002b) also found audio diaries were useful in highlighting creative solutions to problems. Again, this was evident within this study, although interestingly it was perhaps less commonly stated than within the interview study where participants described various innovative approaches to administering eye drops and taking tablets. This may be because most of the audio diary participants had had a visual impairment for some time and so these kinds of activities were not uppermost in their minds. Finally, Papadopoulos and Scanlon (2002b) found that their audio diary study helped to eliminate the stereotypes associated with people who are visually impaired. The findings here support this: the audio diary

participants were engaged in a wide variety of activities, not all of which were related to their visual impairment.

Finally, it is noteworthy to finish this section on strengths by stating how enjoyable and interesting the researcher found this part of the research. The researcher developed a closer relationship with the participant as a result of the longer duration of the study, and really felt that she was part of their lives for four weeks. The transcription of the audio diaries was also particularly exciting as the researcher did not know what the participant was going to say next.

D. Weaknesses of audio diaries

Participants did identify some weaknesses to the audio diary method adopted for this study. Several participants, for example, expressed concern as to whether what they were doing was right, either in terms of using the tape recorder correctly and successfully recording diary entries, or in terms of the diary entries being what the researcher expected. The following quotes illustrate these concerns:

“Well, I wondered whether I was doing it right.” (Audio diarist 1, line 38)

“... at least I hope it's recorded alright ...” (Audio diarist 5, line 28)

“Well ... I was just a little frightened that I wasn't doing enough ... not a lot was really happening ...” (Audio diarist 3, lines 85-86)

None of the participants brought these issues up during the weekly telephone conversations with the researcher, which was surprising. This, therefore, suggests that a follow-up face-to-face visit, perhaps after the first week would have been helpful to review diary entries and reassure participants.

One of the most common weaknesses cited by participants was forgetting to make diary entries each day. For example:

“Oh I forgot from time to time.” (Audio diarist 2, line 25)

In general, participants seemed to remember to make a diary entry at the start of the data collection period, but then their interest seemed to wane somewhat, possibly as a result of running out of things to say. The following quote illustrates this phenomenon:

"I mean you remember it for the first few days ... because ... err ... this is what you're setting out to do ... err ... and then there's sort of a middle period ... err ... where you may miss things ... err ... and then you're thinking ... oh goodness me ... you know ... I'm getting to the end of this particular thing ... I may have to catch up ... erm ... that is where I found ... if there was a weakness." (Audio diarist 3, lines 71-75)

Another possible weakness of the approach identified by participants was the frequency of making diary entries. For example:

"... if I had a difficulty ... it was ... err ... it was my own ... in terms of ... err ... like this has got to be a daily ... and I've got to think of sometime in the day when I've got to sit down and say, well this is what has happened." (Audio diarist 3, lines 20-23)

"It is a chore in the sense that you have to remember to do it every day ... you know ... and it's not always possible ..." (Audio diarist 7, lines 163-164)

Linked to this weakness was the fact that several participants found that, during the course of the four week period, they ran out of things to say. This is illustrated by the following quotes:

"... as time went on in the month ... I thought I've nothing to report. Life goes on ... as usual." (Audio diarist 6, lines 49-50)

"Well ... err ... at the beginning ... it was sort of easier ... because I-I ... you know ... things struck me that you might be interested in ... erm ... but after about a fortnight ... err ... it could have been a lot of repetition ... but ... err ... I did try to think ... err ... things that I know take for granted ... which ... err ... possibly a year or two ago ... would have been ... err ... more dramatic happenings as it were ... or things that were difficult." (Audio diarist 5, lines 21-26)

The second example here highlights the issue behind the problem, that is, although it was originally intended that participants would have been recently diagnosed with a visual impairment, in reality the majority of participants had had a visual impairment for several years and so had now encountered most problems and, therefore, had either identified solutions to them, or accepted them and come to terms with no longer being able to do a particular task, etc. Most participants did not tend to encounter any new difficulties during the course of making their diary, but instead, in response to an event occurring, recalled how they used to find certain aspects of their lives problematic. Despite not being the "live recording" that the researcher had hoped for, the diaries still yielded some very interesting

findings, as discussed in Section 5.4.6. Interestingly, Papadopoulos and Scanlon (2002b) did not identify any specific weaknesses in their study.

E. Suggested improvements to the methodology

When prompted, participants identified two main ways in which the approach adopted for this study could have been improved. The first which has already been alluded to above concerned using the method with people who had recently being diagnosed as being visually impaired, rather than people who had had a visual impairment for several years. This is because newly diagnosed people are likely to encounter more situations and problems for the first time. Collecting data from these people would, therefore, give a real insight into how newly diagnosed people handle new situations and identify solutions to problems. The following quote illustrate this point:

"... I think possibly for newly ... visually impaired people ... it would be more helpful really ... because ... you know ... things will be new to them ... and they've got to ... err ... come to terms with ... err ... how to cope with situations ... whereas ... I've sort of done that in a way ... err ... over the years." (Audio diarist 5, lines 54-57)

Interestingly, one person thought that it would be useful to do a longitudinal study looking at how the information needs of people change over time:

"... it would have been wonderful if you could have had a diary for someone before anything affects them and then when it's all ... as you might say ... over and done with ..." (Audio diarist 3, lines 87-89)

The second way in which one participant in particular thought that the study could have been improved was by making the diary less structured, allowing participants to "tell a story", rather than make a series of daily diary entries:

"I think it's ... better running it as a story, rather than just as entries." (Audio diarist 7, lines 158-159)

Another participant wanted to see the scope of the research expanded to cover more general experiences, rather than just health and social care information needs. Interestingly, most participants did this anyway.

"... the original thing should have been widened ... to include ... general experiences." (Audio diarist 2, lines 54-55).

It was not clear whether these views were shared by the other participants. Although the approach should not be so structured so as to be constraining, there is a fear that by making it unstructured participants would forget to make diary entries and, as acknowledged, by one of the participants themselves, it would make the analysis more complex:

"Makes your job harder ... because you've got to listen to a load of rubbish ... find out what the ... err ... actual best bits are ..." (Audio diarist 7, lines 159-160)

To conclude this section, the following quote from one participant sums up most participants' feelings about the audio diary experience:

"But I have to say ... I think the strengths far outweighed the weaknesses." (Audio diarist 3, lines 75-76)

5.4.8 Research limitations

The main drawback of this research was that a convenience sample of participants was used, many of whom had come forward in response to an advert, as described in Section 5.4.1. This approach emerged because of difficulties associated with recruiting participants via the hospital low vision clinic as originally planned. Although nine names were forwarded to the researcher from the low vision clinic, only five people initially agreed to take part. Two of these people subsequently declined to make an audio diary at the end of the initial interview: one person felt that she would not have sufficient information to record on the diary, and so would forget to make entries, whilst the other person did not feel confident in using the tape recorder after being shown how to use the equipment. Of the three people who initially agreed to make an audio diary, it emerged during the first weekly telephone contact with one of the participants that this person's health had deteriorated and so she no longer felt able to take part in the research. Therefore, the majority of participants volunteered to take part in response to an advert. It is important to note, however, that it was not the intention of this study to obtain a representative sample, but instead to evaluate the suitability of the audio diary method for research with visually impaired people.

5.5 Conclusions and Implications

To conclude, the use of audio diaries with a small sample of older visually impaired people proved to be an enjoyable and beneficial experience, both for the participants and the researcher. Numerous strengths to this methodology have been identified which are summarised below. In addition, a few weaknesses of the specific approach adopted for this study have emerged which can be used to inform future research in this field.

5.5.1 *Strengths of audio diaries*

This study has identified many benefits of using audio diaries as a research method with visually impaired people. Firstly, participants seemed to really enjoy making their audio diaries and took greater ownership of and interest in the research than in the interview study (in accordance with the public involvement philosophy of this research). Secondly, the audio diaries generated 'richer' data than from the interview study and allowed participants' to tell their own stories in their own time. For example, in the audio diaries, participants were able to note small experiences as they occurred, or soon afterwards, which would otherwise have been forgotten about in a one-off interview. The audio diaries also gave an indication of the frequency and context of events. For instance, from the audio diaries, it was possible to identify the format of information as a major concern, whereas this was identified as one of many in the interview study. The longer nature of the audio diaries also allowed solutions to problems to be identified and recorded, such as obtaining information in alternative formats. Finally, the audio diaries emphasised and elaborated on the factors affecting participants' information behaviour, thereby increasing understanding, in particular of their degree of independence, the support they received from friends and family, and their personal acceptance and awareness of their visual impairment.

5.5.2 *Weaknesses of audio diaries*

Three main weaknesses to the audio diary approach adopted for this study were identified. The first of these related to the recruitment of participants. Originally, it was envisaged that the sample would comprise people who had recently been diagnosed as being visually impaired, because these people were likely to have considerable information needs relating to health and social care (in fact this was recommended by participants to

this study). However, recruiting participants via the low vision clinic did not prove very successful for this study. This is not a criticism of audio diaries *per se*, but rather of this particular study. Although the poor recruitment may have been due to staff at the clinic forgetting, it was probably more likely that people at the time of diagnosis had many other concerns and taking part in a research study was not a priority and may have been undesirable. There is evidently a tension associated with involving newly diagnosed people who potentially have the most acute information needs, but who are also experiencing considerable distress and are coming to terms with their visual impairment.

The second of the weaknesses concerned the problems that participants faced remembering to make diary entries and that some people ran out of things to say. Although four weeks may appear to be a long period of time, this timescale was required in order to collect data on the frequency of events. As the participants themselves noted, the main reason for running out of things to say was due to the fact that most participants had had a visual impairment for several years and so had already encountered most situations. The third potential weakness concerned the structuring of the diary, with some participants expressing a preference for a "story-telling" approach. It would be interesting to see how this would work in practice and whether this resulted in more or less frequent diary entries, particularly as the underlying rationale of asking participants to record something every day was to remind them to make an entry. Perhaps adopting a "story telling" approach would result in fewer, but richer, diary entries.

5.5.3 Implications for practice and future research

This research has implications for future research, but also for practice. Although originally envisaged as a research tool by the researcher, this study suggests that audio diaries might be used more generally in health and social care practice with older visually impaired people, particularly to help them overcome changes in their circumstances. This clearly warrants further investigation.

In terms of future research, researchers should be encouraged to use audio diaries as a supplementary method with specific groups of people, particularly older people with visual impairments. It would be interesting for the study reported here to be repeated with a small number of people who have recently been diagnosed as being visually impaired to

see if this yields richer data and addresses some of the weaknesses identified in this chapter.

The research described here is the first in-depth study of the use of audio diaries with visually impaired people. It has substantially advanced our understanding of the value and potential pitfalls of using audio diaries as a research method with older visually impaired people, and supported the underlying public involvement ethos of this research, described in more detail in Chapters 3 and 7. The additional insights into the health and social care information needs of visually impaired people emerging from this study, above and beyond that acquired through the interview study, are elaborated on in Chapter 8.

CHAPTER 6. SURVEY OF MANAGERS OF LOCAL SOCIETIES FOR THE BLIND AND PARTIALLY SIGHTED

6.1 Introduction

The interview study (Chapter 4) and audio diary study (Chapter 5) have started to identify the information needs of people with a visual impairment in respect of health and social care matters, as well as the sources used by visually impaired people to meet their information needs. Interestingly, the local society for the blind emerged as a major information source for many participants. The interview findings in particular also suggested that there was considerable overlap in the information provided by different information providers, with several participants calling for a "one stop information shop" for visually impaired people, *i.e.*, an integrated information service across the health, social care and voluntary sectors. In discussions with the visually impaired advisors to this research, as described in Section 3.9.9 and Chapter 7, it emerged that the finding relating to the importance of the local society as an information source was unexpected given that the focus of the research was on health and social care information. The advisors were also very interested in the concept of an integrated information service for visually impaired people. In addition, as noted in Section 2.2.8, the role of local societies for the blind and partially sighted in meeting the information needs of visually impaired people has not been the focus of any other research in the field.

Therefore, in response to the lack of empirical research, the findings from the interview study and audio diary study, and discussions with the advisors to this research, the researcher decided to undertake a survey of managers of local societies for the blind and partially sighted. Before describing the study in detail, it is helpful to give some background to local societies for the blind and partially sighted.

There are over 100 local societies for the blind and partially sighted in Great Britain. According to NALSVI, the National Association of Local Societies for Visually Impaired People, there is no typical local society for the blind (NALSVI, 2006). The societies differ in size, outreach and in the range of services that they offer. For example, some local

societies are run on a purely voluntary basis, whereas others employ sixty or more staff. Being independent, local societies have to find their own funding, with income coming from contracts with local authorities, trust funds, national lottery programmes, as well as bequests and donations from the public (NALSVI, 2006).

According to Lomas and Vaughan (1987), local societies are those that “... *any visually impaired person should be able to turn to for advice; to be their point of reference to other services; their means of communication with other people having serious sight problems; and a source of practical help*”. In response to the *NHS and Community Care Act 1990* (Office of Public Sector Information, 1990), local societies were able to deliver some social services directly to users via contracts with Social Services departments. Local societies, therefore, appear to have a valuable role to play in meeting some of the information needs of visually impaired people.

6.2 Aims and Research Questions

The main aim of this study was to build on the findings of the interview study, detailed in Chapter 5, and to explore in more detail the role of local societies for the blind and partially sighted in meeting the information needs of visually impaired people. This study was, therefore, designed to answer the following research questions:

1. What information do local societies provide to their clients about health and social care matters?
2. Do the local societies provide the information that the interview participants expressed a need for?
3. What information sources do local societies use to seek information about health and social care matters for their clients?
4. How many local societies seek health and social care information for their clients via the Internet?
5. What do managers of local societies perceive to be the major barriers and facilitators to providing an integrated information service to visually impaired people across the health, social care and voluntary sectors?

6.3 Methods

6.3.1 Study design and justification for the approach

It was decided that a population-based descriptive survey of managers of local societies for the blind and partially sighted would be undertaken in collaboration with NALSVI. The study follows on directly from the interview study and audio diary study by building on two of the particularly interesting findings, as discussed in Section 4.4.6: the key role of the local society in providing information on health and social care matters to visually impaired people; as well as participants' desire for a more co-ordinated approach to information provision. Although it may be argued that the information needs of visually impaired people identified in the Sheffield-based interview study are not necessarily transferable to other groups of these people across the whole of the UK, the emerging information needs were in accordance with Moore's (2002) clusters on information needs identified in his review of the research literature into the information needs of visually impaired people, as described in more detail in Section 8.3.1.

A quantitative approach was most appropriate to adopt because the research was designed to answer a series of 'what' and 'how many' type questions with a large number of respondents, thereby allowing the production of results that could be demonstrated to be rigorous and generalisable (Fox *et al.*, 2001). A high response rate (over 70%) was anticipated due to the research being conducted in collaboration with NALVSI and that NALSVI typically achieves an 80% response rate to its annual user survey.

The survey was supplemented by follow-up telephone interviews with a small sample of local society managers. The aim of these interviews was to clarify and elaborate on the findings from the questionnaire.

6.3.2 Sampling and recruitment

A postal questionnaire in large print was sent in July 2006 to all managers of local societies for the blind and partially sighted in Great Britain that were members of NALSVI (117 at the time of sending out the questionnaire; subsequently 116 due to the merger of two local societies). This was, therefore, a population, rather than sample, survey of local society managers. This method of administering the questionnaire was chosen mainly for

practical reasons, *i.e.*, not all local societies had email addresses, and undertaking the questionnaire by telephone would have been considerably more costly and time consuming. In order to ensure as high a response rate as possible, the research was undertaken in collaboration with NALSVI and two email reminders to those societies that had email and one telephone reminder were made.

The final question on the questionnaire enabled participants to indicate whether or not they would be willing to participate in a follow-up telephone interview. A stratified sample of the local society managers who had indicated their willingness to take part were selected for interview. The sample was stratified according to society size, access to the Internet and use of the Internet to answer clients' queries.

6.3.3 Procedure and materials

A covering letter (Appendix H) and information sheet (Appendix I) were distributed, together with the questionnaire (Appendix J). Respondents were given the option of completing and returning the questionnaire by post in a pre-paid self addressed envelope, over the telephone, or by email. The questionnaire itself comprised three main sections relating to: information provided to clients, information sources used by local societies, and an integrated information service for visually impaired people.

The follow-up telephone interviews with local society managers were semi-structured and covered specific aspects of the questionnaire in more detail: information provided to clients, in particular the provision of information about different eye conditions; the use of the Internet by local societies to answer clients' queries; and the barriers and facilitators to providing an integrated information service for visually impaired people. A copy of the interview topic guide used is provided in Appendix K.

6.3.4 Analysis

All the quantitative data were entered into *SPSS 11.0.1.4 for Windows*. As the survey was population-based and exploratory in nature, only descriptive statistics (*i.e.*, frequencies) were calculated. The qualitative data from the questionnaire were entered into *Microsoft® Excel 2002* and analysed using a simple manual thematic analysis (Lacey and Luff, 2001).

The telephone interviews were transcribed verbatim into *Microsoft® Word 2002* within four weeks of the interview. As the interviews were simply designed to add clarification to the questionnaire responses, again a simple thematic analysis was undertaken using manual coding.

Within-methods triangulation (Denzin, 1978) has been used within this chapter to integrate the findings from the questionnaire and the follow-up interviews. This was done in order to both confirm the findings of the questionnaire, but also to provide a more complete picture of the field.

6.3.5 Trustworthiness

The questionnaire was developed in consultation with the Chair of NALSVI and the visually impaired advisors to this study to ensure that the questions were relevant and worded appropriately. The questionnaire was then piloted with five local societies, selected at random. Managers of four of these local societies responded. Minor changes were made to the wording on the covering letter and the questions in response to this exercise.

Some of the key findings of the survey were discussed as part of the follow-up telephone interviews with local society managers. This enabled the researcher to verify (or otherwise) that the pooled results accurately reflected their views. In addition, a summary of the findings was sent to all societies, inviting participants to comment on them.

6.3.6 Ethical approval

This study was reviewed and approved by the University of Sheffield Department of Information Studies Research Ethics Committee on the 26th May 2006.

6.4 Findings

6.4.1 Response rate

Responses were received from 97 local societies after two email reminders and a telephone reminder. This equated to a response rate of 84%.

In terms of the local societies that did not respond:

- Seven managers did not have enough time to respond,
- Seven managers did not think that the questions were relevant to their local society,
- Two managers were on holiday, and
- Three managers could not be contacted directly.

Sixty-five local society managers indicated that they were willing to discuss their views further via a telephone interview. A stratified sample was identified, as described above (Section 6.3.2). As a result of the sample selection, 14 managers were approached. 1 manager subsequently declined to take part due to work pressures, leaving an interview sample size of 13.

6.4.2 Method of response

The majority of questionnaires (n=83) were returned by post in the stamped addressed envelope provided. In addition, 10 questionnaires were completed over the telephone in response to a telephone reminder, and 4 questionnaires were completed and returned electronically by email in response to an email reminder. The use of reminder systems, therefore, improved the response rate by 14%. Respondents also seemed to appreciate being given the option of completing the form either over the telephone or by email.

6.4.3 Respondent characteristics

The majority of responses (n=46) were received from medium sized local societies, defined as serving a potential population of 501-2,500 visually impaired people. This was followed by small local societies (n=22), serving less than 501 visually impaired people; large local societies (n=19), serving 2,501-5,000 visually impaired people; and very large local societies (n=10), serving more than 5,000 visually impaired people. A higher percentage of non-responders, however, were from small (37%) and medium (53%) sized local societies. This may be because the smaller local societies had fewer staff and/or felt that the questionnaire was less relevant to them, as indicated in Section 6.4.1.

6.4.4 Information provided to clients

Table 4 demonstrates the number of local societies providing information on the topics identified via the interview and audio diary studies, as described in Chapters 4 and 5. Virtually all of the local societies provided information about aids, adaptations and equipment available to visually impaired people (n=95), as well as the health and social care services and facilities available to visually impaired people (n=93). Three-quarters of local societies (n=73) provided information about different eye conditions. Local societies also provided information on benefits and money (n=70), general health care, such as techniques for administering medications and reading medical information (n=69), mobility issues (n=69), housing and accommodation (n=61), and employment, education and training (n=59).

Table 4. The number of local society respondents providing information (written or verbal) on various topics.

Information topic	Number of respondents (N=97)
1. Aids, adaptations and equipment available to visually impaired people, such as visual aids; talking books; liquid level indicators	95
2. The health and social care services and facilities available to visually impaired people	93
3. Different eye conditions, in particular information about the diagnosis, prognosis, treatment options, and causes	73
4. Benefits and money	70
5. General health care, including techniques for administering medications, such as tablets; reading medical information, such as appointment letters, prescriptions, medicine labels, etc.	69
6. Mobility, including using public transport, shopping, eating out, going on holiday, etc.	69
7. Housing and accommodation, including performing household chores, such as cooking and cleaning	61
8. Employment, education and training	59

It was clear from the follow-up interviews that the type and range of information provided varied from society to society. This may be related to the size and nature of the organisation, but also to the knowledge and skills of the local society staff. For example,

“Urm ... you’ll find of course that different societies provide information to different extents.” (Interviewee – Questionnaire Respondent 90, lines 115-116)

Some local societies have their own specialist benefits advisors, community advice officers, and rehabilitation officers and are, therefore, likely to provide information and help with benefits and money, reading medical correspondence, mobility issues and housing and education (NALSVI, 2006). Three-fifths of local societies also provided information about education, employment and training. Several of those societies that did not provide this information, said that they referred clients onto other organisations for this sort of information, such as Action for Blind People.

There was general agreement amongst interview respondents that the main role of local societies was to “signpost” clients to relevant information and sources of support.

“A ... err ... signposter ... to sources of information ... leaflets ... organisations ... experts.” (Interviewee – Questionnaire Respondent 40, lines 37-38)

“It’s often a case of ... err ... pointing people in the right direction though ... err ... rather than giving definitive answers ourselves ...” (Interviewee – Questionnaire Respondent 90, lines 65-66)

“We may not always have the answers ... but ... err ... we’ll have a good try at finding out!” (Interviewee – Questionnaire Respondent 21, lines 74-76)

This is an interesting finding because Swain *et al.* (2007) found that there was a lack of effective signposting in terms of the public accessing health and social care services, with the service user often being left to find the relevant information themselves from the vast array of information available. It appears that local societies are effective signposters, but this is dependent on visually impaired people knowing about their local society in the first place. There is, therefore, a need for further promotion of local society services to visually impaired people.

Interestingly, several local society managers made the distinction between the information their clients needed and what they wanted to know; for example,

“... but we can help people find out what they need ... err ... and want ... to know.” (Interviewee – Questionnaire Respondent 9, lines 47-57)

It was also evident that managers felt that local societies had a role to play in filtering out the most relevant information for their clients:

"I guess our job is also to filter out the rubbish ... I often get calls from people who have heard about miraculous new treatments ... and I'll have to add a note of caution." (Interviewee – Questionnaire Respondent 4, lines 66-68)

"I suppose ... filtering out the ... err ... rubbish ... and ... err ... giving people the information that they want ... err ... when they want it ..." (Interviewee – Questionnaire Respondent 46, lines 46-48)

The following quote from one manager illustrates how local societies try to provide a 'balanced' view of the information on various topics and issues, in order to help their clients make well-informed decisions:

"... it's about ... err ... providing information in a ... err ... I suppose ... unbiased way ... giving people the ... err ... information that they need in order to ... err ... to make a decision about whether ... something is suitable for them ... or whether they wish to pursue something further." (Interviewee - Questionnaire Respondent 65, lines 56-59)

Although some local societies appeared to be using the same information, there did appear to be some duplication of effort, with societies generating their own information locally and not necessarily sharing this with others. For example,

"I'm sure we'll all be doing something slightly different ... not that it matters I guess ... it's just we may be all reinventing the wheel ... as it were." (Interviewee - Questionnaire Respondent 21, lines 92-97)

It was interesting to find that such a large proportion of local societies provided information about different eye conditions. One of the managers interviewed specifically commented on this:

"I suppose I'm surprised some of the local societies are able to provide information about different eye conditions. I would ... err ... see our role as ... err ... more as ... err ... you know ... directing people to other sources of information ... experts ... rather than they ... us informing people." (Interviewee - Questionnaire Respondent 9, lines 37-41)

From the survey findings, it was not clear whether local societies were simply re-using information on eye conditions (e.g., leaflets) produced by national organisations, such as the RNIB, or whether they were writing their own information. The interviews with managers shed some light on this: most used existing leaflets produced by the RNIB

and/or Royal College of Ophthalmologists, although some also searched the Internet for information on specific, often rare, conditions. For example,

"It depends ... most is from the RNIB ... the pre-printed leaflets ... but sometimes we have had to locate specific information on the web ... you know ... either for very rare conditions ... or ... err ... more detailed information." (Interviewee - Questionnaire Respondent 9, lines 62-65)

"It's virtually always existing leaflets ... we don't have the time or energy to ... err ... start writing our own ... and ... err ... anyway, why would we need to?" (Interviewee - Questionnaire Respondent 40, lines 44-46)

"Oh yes ... we try and re-use as much information as we can." (Interviewee - Questionnaire Respondent 86, lines 59-60)

It would be interesting to look in more detail at the content of these leaflets to determine the extent to which they followed a mechanistic model of communication whereby patients are characterised as passive and open to manipulation in the interests of a biomedical agenda (Dixon-Woods, 2001). Hopefully the more recent leaflets will draw upon the current agenda to empower patients, for example, by presenting a wide of options and possible outcomes (Dixon-Woods, 2001). However, this warrants further investigation.

It was evident that most local society managers were confident that the information they provided on different eye conditions was reliable and up to date, as illustrated by the following quote:

"You can also be reassured that the information is accurate ... many of the leaflets are written by experts ... err ... and they are updated on a regular basis ..." (Interviewee - Questionnaire Respondent 4, lines 78-80)

"Well ... err ... yes ... I mean we're simply using leaflets that others are across the country. The leaflets have been written by experts so ... err ... it should be accurate and reliable ... at least I've always assumed it to be!" (Interviewee - Questionnaire Respondent 78, lines 68-71)

"Well ... as much as I ... err ... trust any information!" (Interviewee - Questionnaire Respondent 90, lines 103-104)

Interestingly, whereas the first two managers seemed to equate accuracy and reliability with "experts", the third manager was more sceptical and indicated that he was cautious about all information.

However, it also emerged that some local society managers had not really considered the issue of reliability; for example:

“Seriously ... err ... I haven’t given it much thought ... that sounds bad, doesn’t it? ... I mean I just take it for granted that the staff ... err ... we have ... are excellent ... err ... and take care with the information they provide ... using existing materials ... like the RNIB leaflets wherever possible.”
(Interviewee - Questionnaire Respondent 46, lines 69-73)

In terms of reliability of information sources and tools, one local society manager appeared to regard Google as an equally reputable source as national visual impairment organizations. This suggests that some staff at local societies may require training in assessing the quality of information, particularly on the Internet.

“... we always use reputable sources ... RNIB, Action for Blind People ... Macular Disease Society ... Google ...” (Interviewee - Questionnaire Respondent 61, lines 55-57)

This suggestion is supported by Coulter (1998) who called for investment in the production of higher quality, evidence-based patient information, training for clinicians and other information providers in how to use them, and the development of an accreditation system (e.g., kite marks) to help users judge the quality of information.

The interview question also prompted a few local societies to investigate the reliability and currency of information provided by their staff further:

“It’s a ... err ... good question though ... err ... and has got me thinking! I certainly ... hope none of our staff give out their ... err ... own personal opinions about ... well ... particularly treatments ... how effective they are ... that sort of thing. We’ve ... err ... got a team meeting on ... err ... Monday morning ... I ... err ... think I’d better raise the issue there! Thank you.” (Interviewee - Questionnaire Respondent 46, lines 74-79)

“Mmm ... that’s just reminded me ... I need to check we have the most recent versions ...” (Interviewee - Questionnaire Respondent 4, lines 80-81)

It is also noteworthy that some local societies did not provide information to clients about different eye conditions, and thought that this was the responsibility of trained health professionals:

“... we do not provide information ... err ... ourselves about ... err ... eye conditions ... if we were to I think I would be ... err ... a bit more concerned

about the ... reliability ... trustworthiness ... err ... of the information.”
(Interviewee - Questionnaire Respondent 65, lines 75-80)

“Well ... from ... err ... our point of view ... we ... err ... don't give out information about ... err ... eye conditions ... we ... err ... just ... err ... do not ... feel ... err ... qualified to ... err ... do so. No ... err ... we ... err ... leave ... that to the ... experts.” (Interviewee - Questionnaire Respondent 94, lines 33-37)

Several local society managers also thought that the timing of information provided to visually impaired people was crucial and that the local societies had an important role to play in reinforcing information already provided by others, in particular the ophthalmologists. For example:

“I'm not convinced the information we are providing is new ... but maybe it's in more digestible chunks ... and ... err ... at a better time for them.”
(Interviewee - Questionnaire Respondent 4, lines 95-97)

“... you see people often come to us having been told nothing ... or ... err ... at least very little ... or maybe they can't remember what they've been told. By the time they come to us ... they're usually better able to ... err ... digest ... the information ... I'm talking particularly in terms of their eye condition ... you know ... treatments ... outcomes ... things like that.”
(Interviewee - Questionnaire Respondent 46, lines 48-53)

“... the doctors ... although they are fantastic in what they do ... they ... err ... just do not have the time ... or ... to be honest ... err ... the ... err ... skills to provide people with the ... right information ... when diagnosing someone as being sight impaired. Also ... most people cannot accept and ... err ... process this information at this difficult time.” (Interviewee - Questionnaire Respondent 90, lines 82-87)

6.4.4.1 Format of information

As shown in Table 5, the majority of information provided by local societies was verbal, either face-to-face (n=48), or over the telephone (n=16). Information was also provided in alternative formats, but to a lesser extent; for example, in large print (n=13), audio cassette (n=2), CD (n=1) and talking newspaper (n=1).

It should be noted that there were 16 missing answers to this question. This is mainly because respondents misread the question and listed all the different formats in which they provided information. Unfortunately this issue did not arise during the pilot, as described in Section 6.3.5, and, therefore, could not have been anticipated.

Table 5. The format most of the information is provided to visually impaired people by local society respondents.

Format	Number of respondents (N=81)
1. Verbal – face-to-face	48
2. Verbal – over the telephone	16
3. Large print	13
4. Audio cassette	2
5. CD	1
6. Local talking newspaper	1

Interestingly, the vast majority of information (almost four-fifths) provided to clients by local societies was done so in a verbal manner, and most of this information was delivered face-to-face. It is not clear from this survey how this information was delivered; for example, whether it was on an individual or group basis. Participants in the interview study had certainly expressed a preference for face-to-face information. However, they also wanted written (or taped) information as well. Again, it is not clear if local societies followed up initial verbal information with more detailed information in an alternative format.

6.4.4.2 Targeting of information

Thirty-six local societies targeted their information to particular groups of clients. Most of these societies targeted the information by age group (n=14), followed by other means, such as geographical location (n=11), by eye condition/ diagnosis (n=6), and time since registration (n=4). There was also 1 missing answer.

One of the improvements that participants in the interview study had requested was more targeting of information to individuals. It is, therefore, interesting to find that only just over one third of local societies actually targeted their information at particular client groups. This suggests that, although clients may be receiving a lot of information, some of this information may be irrelevant to them, despite the apparent efforts of some local societies.

6.4.5 Information sources used by local societies

Table 6 lists the information sources used by local societies to seek answers to clients' queries about health and social care matters. The top five sources of information were national societies, such as the RNIB and Macular Disease Society (n=86), a Rehabilitation Officer for Visual Impairment (ROVI) (n=85), the hospital eye department, including the low vision clinic (n=76), the Internet (n=74), and colleagues at other local societies (n=72). Less well-used sources included social workers, opticians, the mass media, general practitioners and NHS Direct. Respondents also suggested several other sources of information, including in-house rehabilitation officers, benefit agencies, etc.

Table 6. The information sources used by local society respondents.

Information source	Number of respondents (N=97)
National societies (e.g., RNIB, Macular Disease Society)	86
A rehabilitation officer for visual impairment (ROVI)	85
The hospital eye department (including the low vision clinic)	76
The Internet	74
Colleagues at other local societies	72
A social worker	55
A local optician	26
The mass media (e.g., newspapers, magazines, television, radio)	23
A local general practitioner	19
NHS Direct	12
Other	10

As might have been expected, national and local visual impairment organisations, as well as the hospital eye department, figure highly on the list of information sources used by local societies. Although specialist rehabilitation officers are well used by local societies, generic social workers are not used as extensively as an information source. This may be because generic social workers do not usually receive specialist training in supporting people with a visual impairment. Interestingly, more than three-quarters of respondents indicated that they used the Internet to answer clients' queries.

6.4.5.1 Internet use by local societies

Ninety-one local societies had Internet access at their local society, and 73 local societies used the Internet to answer clients' queries. Interestingly, several local society managers who were interviewed questioned why not all the local societies were using the Internet:

"Mmm ... I wonder why ... err ... the 18 societies didn't?" (Interviewee - Questionnaire Respondent 9, lines 89-90)

"I suppose I'm ... err ... surprised that ... err ... in this day and age ... there are ... err ... still some local societies that ... err ... do not have Internet access!" (Interviewee - Questionnaire Respondent 46, lines 90-92)

Sixty-seven respondents gave an example of the information that they had sought for a client using the Internet. Most of these examples related to equipment designed for visually impaired people (e.g., computer hardware and software, mobile telephones, talking alarms, etc.), rare eye conditions, and details of local support groups. Societies were also using the Internet, albeit to a lesser extent, to find out information about specialist holidays and transport for visually impaired people, as well as benefits advice, and how clients could participate in local visual impairment research.

The follow-up interviews with local society managers highlighted some of the advantages of using the Internet over other sources of information, in particular the speed of getting an answer to specific or difficult queries:

"... gave me an immediate answer. In the past ... it would have taken me days ... if not weeks to find an answer to that one." (Interviewee - Questionnaire Respondent 9, lines 95-97)

"... it's very useful for tricky queries ... or when you want information quickly ..." (Interviewee - Questionnaire Respondent 61, lines 69-70)

"We are making increasing use of the Internet as we are able to provide information instantly rather than have to get back to people." (Questionnaire Respondent 41)

From those questionnaire respondents that stated the web sites they had used, it was evident that the most commonly used sites were national organisations, in particular the RNIB and Action for Blind People, as well as search engines (such as Google). The following example illustrates how many people were using the Internet:

"A parent came to see us about their seven year old son who had been diagnosed with cone dystrophy but they had little information about his condition. I was able to find out information they had not seen from the RNIB's web site." (Questionnaire Respondent 59)

Thirty-four questionnaire respondents provided additional comments about the Internet: 21 of these comments were positive, nine were neutral and four were negative. The Internet was generally seen as a valuable tool for visually impaired people, as well as by the local societies themselves. For example:

"I find it very useful for information on rare eye complaints/ conditions, often there is very little information for people who have been newly diagnosed." (Questionnaire Respondent 67)

"It's a useful tool by which to gain information and to keep up to date with what other local societies are doing. Also to keep up to date with the political debate on health and social care issues and to check reports and research findings". (Questionnaire Respondent 13)

However, several respondents highlighted some of the barriers to Internet use, including locating relevant information, the need for ICT skills training, and the expense of purchasing specialist equipment. For example:

"It can often be very difficult to locate what you are looking for!" (Questionnaire Respondent 102)

"It's often not very accessible for users who have basic IT skills and visual impairment." (Questionnaire Respondent 109)

Another major concern which emerged from both the survey and follow-up interviews with local society managers was the quality of information on the Internet:

"Need care to check info source is reliable and up to date." (Questionnaire Respondent 48)

"I am fearful of using it too much though ... or of encouraging our volunteers to ... there's so much rubbish out there ... and it's not always easy to identify the fake claims." (Interviewee - Questionnaire Respondent 4, lines 112-114)

This latter quote supports Coulter's (1998) belief that many "professionals" adopt the paternalistic view that service users and patients cannot cope with the truth and must be kept ignorant of uncertainties.

Interviewees reported that they adopted various strategies in order to reassure themselves of the validity of the information found on the Internet. This mainly involved looking only at reputable sites, such as national visual impairment organisations, as well as checking who wrote the information and when.

"Err ... by sticking to known sites ... RNIB ... Action for Blind People ... if I can't trust them ... who can I?" (Interviewee - Questionnaire Respondent 40, lines 72-73)

"By looking at the authors ... whether the facts are referenced ... the date of publication ... is it out-of-date ... err ... I think those are the main things I tend to look at." (Interviewee - Questionnaire Respondent 61, lines 73-75)

Most interviewees also tended to avoid personal and/or opinion-based web sites, but were concerned that not everyone would be able to identify these.

"Generally, I stay clear of personal web pages ... although independent reviews of products can be really useful." (Interviewee - Questionnaire Respondent 4, lines 119-120)

"I'm very wary of all these advertiser sites ... I think many are out there to get as much as they can from vulnerable people." (Interviewee - Questionnaire Respondent 21, lines 111-114)

Some interviewees found it difficult to pin down how they made a decision about whether to trust the information they found on a web site:

"Well ... err ... I suppose you ... err ... just get a 'feel' ... don't you? It's a bit like when you're shopping online ... and you look out for the security symbol ... lock ... you know what I mean?" (Interviewee - Questionnaire Respondent 9, lines 100-102)

It was also acknowledged that it was potentially even harder for visually impaired people to identify high quality and reliable sources of information on the Internet:

"It ... err ... is ... getting increasingly difficult, however ... companies are getting sneakier ... copying official site designs ... And ... I suppose ... err ... identifying those sites is even harder if you're blind." (Interviewee - Questionnaire Respondent 46, line 109-111)

Overall, however, respondents to the questionnaire and interview participants thought that the Internet would become increasingly important in helping visually impaired people to

lead independent lives by allowing them to access the information that they wanted at a time that suited them. This is illustrated by the following quotes:

"Internet use will increase as the generational shift takes place and "younger" people with IT skills replace the "non tech" generation". Emphasis will shift from "I can't use it – teach me" to "How do I continue to use it". (Questionnaire Respondent 46)

"The Internet is a great tool that visually impaired people can use independently to find answers to their own questions." (Questionnaire Respondent 3)

"The wealth of software and ... err ... hardware out there ... screen readers ... accessibility software ... speech synthesisers ... means that ... err ... more and more ... blind and partially sighted people can access information for themselves that ... err ... they never have been able to do so before ... it helps with independence ... gives them choice ... a key thrust of the ... err ... government's new White Paper." (Interviewee - Questionnaire Respondent 90, lines 143-148)

6.4.5.2 NHS Direct use by local societies

Although the majority of respondents (n=92) to the questionnaire had heard of NHS Direct (or NHS 24 in Scotland), only 15 local societies had ever directed any of their clients to use it in connection with their eye condition. 18 respondents made specific comments about NHS Direct. Most of these comments were negative and questioned the relevance of NHS Direct to visually impaired people. For example:

"Of little impact on older sight impaired who prefer to use surgeries and their GP." (Questionnaire Respondent 46)

"The information available on sight loss is limited. In the main, the work of local societies relates to the social care element, dealing with the effects of sight loss rather than the cause, so there is limited benefit from NHS Direct." (Questionnaire Respondent 85)

"Hope it doesn't become the target for money saving." (Questionnaire Respondent 105)

Several respondents had used it personally, but had not found the advice given particularly helpful:

"Personally I have used it, but I didn't find it very useful and so ended up going to see my GP." (Questionnaire Respondent 24)

It is remarkable how infrequently local societies reported directing their clients to use NHS Direct. NHS Direct, delivered over the telephone and online, has the potential to provide accessible information to visually impaired people. Although it was clear that some respondents questioned the quantity and quality of information about eye conditions on NHS Direct, it was also evident that managers' own personal experience (good and bad) of NHS Direct appeared to influence their decision as to whether to direct their clients to use this information resource.

6.4.6 An integrated information service for visually impaired people

The interviews with local society managers yielded mixed views on the concept of an "integrated information service" for visually impaired people. This may be because managers interpreted an integrated information service in different ways, ranging from different agencies simply working together more closely, to the local societies being totally responsible for a "one stop information shop". Several managers, for example, thought that they were already involved in running an integrated information service for visually impaired people at a local level:

"Overall ... err ... I suppose I was a bit confused by the suggestion ... I mean ... that's what we're all trying to do now, isn't it?" (Interviewee - Questionnaire Respondent 116, lines 79-80)

"... if you mean ... in terms of working together ... err ... more closely ... then ... err ... yes, I think this is ... err ... already happening. The White Paper's certainly making us do that!" (Interviewee - Questionnaire Respondent 86, lines 92-94)

"That's a difficult one ... I have to say I'm not convinced ... in some ways that's what we're trying to do in the voluntary sector anyway ... so it would just be a case of formalising it." (Interviewee - Questionnaire Respondent 40, lines 79-81)

Some managers were very enthusiastic about being involved in an integrated information service for visually impaired people:

"Well, I've been harking on about this for years! And I'm fed up with hearing, "in your dreams ... it'll never happen"! I believe ... sorry for the corniness ... but ... err ... "if there's the will, there's the way!" The White Paper on health and social care ... you know ... the one with all the 'ours' in it? ... well, that's all about integrated working ... joined up services ... putting the service user first. It's really just a matter of time. It ... err ... will

... err ... and must happen." (Interviewee - Questionnaire Respondent 9, lines 111-117)

Several managers were sceptical, however, and, although they thought that an integrated information service was a good idea in theory, they felt that it would be difficult to implement; for example,

"I mean ... in theory it's a great idea ... but ... err ... in practice ... let's be realistic ... it's ... err ... never going to happen! There are too many differences ... too many big egos ... empire builders ... bureaucratic red tape!" (Interviewee - Questionnaire Respondent 4, lines 128-131)

"As an idea ... great ... in ... err ... practice ... I have to be honest and ... err ... can't ever really seeing it happen." (Interviewee - Questionnaire Respondent 21, lines 125-126)

Interview participants also expressed concern, usually based on previous experience, that a joint information service may become dominated by the statutory organisations, *i.e.*, the NHS and Social Care, and that local societies would lose their independence. The following quotes illustrate this point:

"In my experience statutory organisations are basically "ticking boxes" to meet Government targets. When meetings with voluntary organisations and statutory organisations are arranged they are always led by the statutory organisation that is focusing on whatever is the agenda with the other statutory organisations who are present using jargon invented for that particular topic. The outcome in my experience is often valueless unless taken up one or more of the voluntary organisations who are often the only organisations present who actively make a difference rather than sit around talking about it!!!!" (Questionnaire Respondent 47)

"Trying to work across boundaries ... err ... never really works ... the statutory organisations always try to "control" ... the voluntary organisations always ... err ... do all the work ... well ... err ... that's ... err ... definitely been my experience!" (Interviewee - Questionnaire Respondent 21, lines 126-129)

"It's also important for organisations like us to ... err ... remain independent ... that's what our clients like about us ... and allows us to be flexible. My fear would be that ... we would be ... err ... taken over by the statutory organisations ..." (Interviewee - Questionnaire Respondent 46, lines 120-123)

6.4.6.1 Barriers to providing an integrated information service for visually impaired people

Over three-quarters (n=78) of respondents to the questionnaire felt that conflicting priorities of different organisations acted as a barrier to providing an integrated information service for visually impaired people across the NHS, social care and voluntary sectors. This was followed by budget constraints (n=74) and concerns about sharing personal information (e.g., in response to the Data Protection Act) (n=70). Other barriers cited by participants included inability to share information due to incompatible information/computer systems (n=57), separate budgets for each organisation (n=36), unsuccessful attempts to work together in the past (n=33), differences in terminology used (n=29), cultural differences (n=23), fear of job losses (n=21) and other barriers (n=21). The 'other' barriers cited were trust, particularly between the NHS, social care and voluntary agencies; a lack of understanding and experience of information sharing; awareness of each other's work; the low priority given to visual impairment within the NHS; and time required to develop networks.

When asked what was the biggest barrier to providing an integrated information service for visually impaired people, the following three issues emerged as the most important, as shown in Table 7:

- Concerns about sharing personal information (n=25)
- Conflicting priorities of different organisations (n=24)
- Budget constraints (n=21)

Although there were similarities between the responses given to questions 3.1 (which are barriers?) and 3.1.1 (the biggest barrier), there were also some discrepancies. For example, although 72% of respondents felt that concerns about sharing personal information was a barrier, this was perceived to be the biggest barrier by only 27% of respondents. However, the top three barriers were consistent across questions 3.1 and 3.1.1.

Table 7. The biggest barriers to providing an integrated information service for visually impaired people across the NHS, social care and voluntary sectors, as perceived by the local society respondents.

Barrier	Number of respondents (N=93)
Concerns about sharing personal information (e.g., in response to the Data Protection Act)	25
Conflicting priorities of different organisations	24
Budget constraints	21
Inability to share information due to incompatible information/ computer systems	9
Fear of job losses	8
Separate budgets for each organisation	2
Differences in terminology used	2
Cultural differences	1
Other	1
Unsuccessful attempts to work together in the past	0

The follow-up interviews allowed the reasons behind these top barriers to be explored in more detail. In terms of sharing personal information, managers' concerns seemed to stem from too strict enforcement and/or misunderstanding of the Data Protection Act, with the default position being not to share information between different agencies. The following quote summarises the situation:

"Mmm ... the Data Protection Act ... certainly has a lot to answer for! I know it was set up for good reasons, but it is so often used as an excuse these days. Sharing of information between local societies, Social Services and the hospitals is a real problem ... and the situation varies across the country. No-one knows whether they're doing the right thing ... if in doubt ... the approach seems to be not to share! In the past ... I'm sure it was the reverse!!" (Interviewee - Questionnaire Respondent 4, lines 140-146)

It should be noted, however, that some interviewees reported examples of good information sharing practice:

"... it ... err ... doesn't seem to be a problem here ... the nurses at the hospital ... get the person's consent to ... err ... pass on their details to us ... very few people ... seem to refuse ..." (Interviewee - Questionnaire Respondent 116, lines 98-100)

Interview participants also thought that there were simple solutions to this barrier, namely training staff in the principles and application of the Data Protection Act, and establishing

information sharing agreements and/or protocols, whereby consent is obtained at the time of diagnosis at the hospital to pass on a person's contact details to the local society.

"Going back to the issue of data protection ... I think we all need proper training ... what does it mean? ... what information can we share? when? ... do we always need explicit consent from the client?" (Interviewee - Questionnaire Respondent 4, lines 166-168)

"If only they could ask the service user at the time whether they minded having their details passed on. I ... err ... mean ... it's not ... err ... even as though we ... err ... going to harass them ... or ... err ... anything like that! We want to help ... err ... and if they don't want help ... then that's fine ... that's ... err ... their choice." (Interviewee - Questionnaire Respondent 9, lines 124-133)

The recent White Paper, *Our Health, Our Care, Our Say* (Department of Health, 2006b) should help to improve the way information is shared between health and social care providers, and there definitely seems to be a shift by central government to share information automatically with other agencies rather than prevent it.

The issue relating to conflicting priorities of different organisations was clearly a major concern amongst interview participants, as illustrated by the following quotes:

"Now ... conflicting priorities ... my experience is ... more a lack of priorities ... that's really been our problem." (Interviewee - Questionnaire Respondent 65, lines 144-145)

"For me personally ... the conflicting priorities ... or probably more correct ... lack of priorities ... is the ... biggest barrier. If we cannot agree then ... err ... how can we move forward?" (Interviewee - Questionnaire Respondent 78, lines 80-82)

It is hoped that recent drives to integrate health and social care services through mechanisms such as pooled budgets and joint commissioning (Young, 2006) will help to remove such conflicts and barriers.

Interview participants found it harder to suggest approaches to overcome this barrier:

"Not sure what you can do about them ... I mean how do you get people to agree the same priorities ... particularly when they are governed and funded through completely different routes." (Interviewee - Questionnaire Respondent 4, lines 148-151)

However, several local society managers thought that local strategies and/or agreements would help to clarify priorities:

"... what we need is ... a local agreement on what it is we are all trying to achieve and ... err ... who's going to do what." (Interviewee - Questionnaire Respondent 90, lines 183-184)

Interview participants had different perceptions concerning budget constraints, with some local society managers believing this was a genuine barrier, whereas others believed people used this as an excuse. For example:

"... the eternal budget constraints ... this has been and will continue to be a major issue." (Interviewee - Questionnaire Respondent 4, lines 151-152)

"... not budget constraints though ... that's just an excuse!" (Interviewee - Questionnaire Respondent 9, line 124)

Several managers alluded to activities and services that they would provide if more money was available:

"There's so much we ... err ... want to do ... err ... to help people ... like have more outreach services ... but ... err ... just do not have the money to do so. That's ... err ... very frustrating and ... err ... at times ... upsetting ... particularly when you try to explain the situation to clients ... they ... err ... just want someone to visit them ... mmm ... yes, it can be very sad." (Interviewee - Questionnaire Respondent 61, lines 90-95)

Although some managers thought that the answer was straightforward:

"... give us more money!" (Interviewee - Questionnaire Respondent 61, line 110)

others thought that the solution was more complex:

"... no matter how much money you put in ... err ... you'll always want more ... just err ... look at the NHS." (Interviewee - Questionnaire Respondent 65, lines 143-144)

"... it's more a case of ... err ... not always putting the money where it's needed ... in the NHS ... for example, visual impairment ... well actually sensory impairment ... is ... err ... seen as a minor thing ... it's ... err ... not like cancer ... something like that that gets lots of investment. Even in Social Services ... there are very few specialist rehabilitation officers ... social workers ... most are generic ... and ... err ... refer people on to ... err ... the voluntary sector ... like us ... anyway." (Interviewee - Questionnaire Respondent 61, lines 101-107)

Interestingly, several local society managers felt that many of the barriers cited were perceived, and not necessarily substantiated with evidence. For example:

"Barriers are often perceived ... err ... rather than real though ... and we must all remember that". (Interviewee - Questionnaire Respondent 40, lines 94-97)

It also emerged that organisations as a whole, as well as key post-holders had a major role to play in determining the presence and extent of these barriers.

"Organisations themselves can be restrictive ... individuals can be ... err ... obstructive ... you really need both to be flexible." (Interviewee - Questionnaire Respondent 78, lines 88-90)

"We have found the personnel holding key posts is an important factor in joint working and information. If a key postholder does not share the same view of how to fulfil common stated objectives, nothing constructive can happen." (Questionnaire Respondent 65)

"Definitely having ... enthusiastic people in key posts helps ... pushes things through ... quicker than would happen otherwise." (Interviewee - Questionnaire Respondent 46, lines 143-144)

"That's a tricky one ... perhaps both. Organisations ... particularly large ones ... like the NHS and Social Services ... err ... have a tendency to get obsessed with ... err ... processes and ... err ... sometimes forget about ... outcomes. I don't think it's ... err ... deliberate ... it's just the nature of large organisations. Certainly we have found our progress on initiatives has been ... hampered or ... hindered by key personnel ... for example ... people will interpret procedures in either a positive or negative way ..." (Interviewee - Questionnaire Respondent 90, lines 195-201)

Past experiences, both positive and negative, seemed to influence managers' comments about barriers to providing an integrated information service for visually impaired people.

This is demonstrated by the following comments:

"... if you've had bad experiences in the past you are ... wary ... cautious ... aren't you? I think people are ... sometimes fearful ... of ... err ... trying as well." (Interviewee - Questionnaire Respondent 94, lines 85-87)

"There was just one person leading on it ... and ... err ... she ... changed jobs ... so it all just seemed to come to an end. It was so frustrating at the time ... we had given a lot of time and ... err ... energy to ... that initiative ... and ... err ... so had a lot of our service users ... many of them still ask whatever happened to that regional strategy? It could have been a great example of excellent ... joint working ... but ... err ... instead ... it reinforced the need to ... err ... go your own way ... to ensure things get done!" (Interviewee - Questionnaire Respondent 90, lines 185-191)

However, most interview participants were able to identify ways in which the barriers could be overcome. Most of the suggestions centred on the key players actually coming together and agreeing objectives, priorities and funding.

"... it's just common sense really ... we need to come to agreements about who's doing what, when and where ... and who's paying for what ..."
(Interviewee - Questionnaire Respondent 21, lines 156-158)

"... trying to get all the people who need to be together and making them agree ... that would ... err ... at least be a step in the right direction!"
(Interviewee - Questionnaire Respondent 78, lines 93-95)

There was also a feeling that the recent White Paper on health and social care (Department of Health, 2006b) was already starting to encourage more joint working.

"I think the White Paper may ... err ... force us to look at more integrated working." (Interviewee - Questionnaire Respondent 86, lines 114-116)

It was suggested that local societies needed to pay closer attention to the performance agenda within health and social care:

"... I suppose we need to tie it all in more closely with the ... err ... performance agenda ... within the NHS and ... now even Social Services ... maybe what we need are ... err ... shared performance indicators ... now that ... err ... really would get people's backs up ... but ... I do ... err ... think that would help." (Interviewee - Questionnaire Respondent 65, lines 163-169)

This is also in line with the views of Lomas (2000) who advocated placing a greater emphasis on outcomes, for example, demonstrating the effects that local societies have on the health and well-being of service users.

6.4.6.2 Facilitators to providing an integrated information service for visually impaired people

Nearly one in four respondents (n=25) thought that the active involvement of visually impaired people in shaping services was a facilitator to providing an integrated information service to visually impaired people across the NHS, social care and voluntary sectors. This was followed by existing good relations with other organisations (e.g., joint meetings and groups) (n=79), local and/ or regional strategies for visually impaired people/ visual impairment services (n=74), and local and/ or regional information sharing protocols/

agreements (n=71). Other facilitators cited by respondents included compatible information/ computer systems (n=54), examples of previous successful integrated working (n=42), shared budgets (n=33), and other facilitators (n=8). The 'other' facilitators related to having enough time and money to set up new agreements and systems, adopting shared objectives, and more commitment nationally and locally to develop such a service.

When asked what was the biggest facilitator to providing an integrated information service for visually impaired people, the following four issues emerged as the most important, as shown in Table 8:

- Local and/or regional strategies for visually impaired people/ visual impairment services (n=27)
- Active involvement of visually impaired people in shaping services (n=25)
- Existing good relationships with other organisations (e.g., joint meetings and groups) (n=15)
- Local and/ or regional information sharing protocols/ agreements (n=11)

Table 8. The biggest facilitators to providing an integrated information service for visually impaired people across the NHS, social care and voluntary sectors, as perceived by the local society respondents.

Facilitator	Number of respondents (N=89)
Local and/or regional strategies for visually impaired people/ visual impairment services	27
Active involvement of visually impaired people in shaping services	25
Existing good relationships with other organisations (e.g., joint meetings and groups)	15
Local and/ or regional information sharing protocols/ agreements	11
Other	6
Compatible information/ computer systems	4
Shared budgets	1
Examples of previous successful integrated working	0

Similar to the barriers, described in Section 6.4.6.1, it is interesting to compare the responses to questions 3.2 (which are facilitators?) and 3.2.1 (the biggest facilitator). The

top four facilitators (local and/or regional strategies for visually impaired people/ visual impairment services, active involvement of visually impaired people in shaping services, existing good relationships with other organisations, and local and/or regional information sharing protocols/ agreements) were consistent across the two questions, but the ordering was slightly different. For example, 89% of respondents felt that the active involvement of visually impaired people in shaping services was a facilitator, whereas, as shown in Table 8, only 28% felt that this was the biggest facilitator.

The issue of effectively engaging visually impaired people in designing services was highlighted by many of the managers interviewed. This was reassuring to find, as it reinforced the user involvement elements of this research study. The importance of doing so was clear amongst participants:

"The involvement of our clients is essential ... we need their help for us to help them." (Interviewee - Questionnaire Respondent 40, lines 111-112)

However, several participants acknowledged that user involvement did not happen as often as it should:

"I'd agree with that ... particularly about involving blind and partially sighted people ... that's crucial and ... err ... really doesn't happen as much as it should ... unfortunately ... err ... it's still often seen as an "add-on" ... when ... err ... really it's essential ... and the building block of all that we do ... I mean ... how can we deliver services to these people if we don't ask them what they want? I know it sounds simple, but ... err ... that message seems to get lost sometimes." (Interviewee - Questionnaire Respondent 21, lines 166-172)

One participant even gave an explanation as to why he thought users were not always involved:

"I know it can be difficult ... and ... we all fear things becoming dominated by one or two individuals ... we all have them ... the people that always have too much to say ... have to complain about everything ... you know what I mean? ... but ... it doesn't mean ... we ... err ... shouldn't try." (Interviewee - Questionnaire Respondent 116, lines 123-126)

Interestingly, Lomas (2000) specifically addressed the terminology used by local societies and discusses some of the pros and cons of renaming local societies to "of the blind and

partially sighted”, rather than “for the blind and partially”, thereby demonstrating a more emancipatory approach (Beresford, 2002).

Several of the managers interviewed also specifically commented on the need for effective regional strategies for visually impaired people, but had reservations about how these might work in practice:

“Strategies to me are often meaningless pieces of paper ... unless of course blind people are involved in writing them!” (Interviewee - Questionnaire Respondent 4, lines 182-183)

“... a strategy is one thing ... an action plan ... and delivering that strategy is ... err ... another!” (Interviewee - Questionnaire Respondent 65, lines 185-187)

The following quote aptly describes the benefits of the different agencies working together:

“All the different agencies need to ... err ... come together and agree what it is that we want to achieve ... remembering that ... err ... with limited resources we ... err ... cannot possibly do everything. We also need ... to ... err ... overcome this err ... fear of working across organisations ... joined up working is definitely the way to go ... but people are fearful ... it's beyond their comfort zone ... what happens if it all goes wrong? The thing that people do not realise is that by ... err ... working together ... we'll save on time and effort ... we'll be able to stop so much duplication of what we do ... and ... err ... start meeting more our clients' needs. We'll often ask people what they want ... but how often do ... err ... can we ... actually then provide them with what they want. That's a real issue.” (Interviewee - Questionnaire Respondent 65, lines 144-155)

Although the presence of good relationships with other organisations was considered an important facilitator, most local society managers were unable to give specific examples of where joint working had been a success. The following quotes were typical:

“... I wish I could give a good example ... but ... err ... if I'm honest ... I can't!” (Interviewee - Questionnaire Respondent 9, lines 168-169)

“Mmm ... I can give you many examples ... but not sure they've been a success! Most have been very small-scale initiatives working with positive individuals ...” (Interviewee - Questionnaire Respondent 21, lines 175-177)

Having said that, a few managers did refer to successful joint ventures, particularly in relation to the running of hospital eye information desks:

"I suppose the best example I can give you is our hospital information desk ... that's a voluntary initiative based in the hospital, but with NHS and Social Services support." (Interviewee - Questionnaire Respondent 4, lines 187-189)

However, it was acknowledged that these initiatives only tended to work because of the specific individuals involved:

"... that pilot was ... to be honest a ... real struggle and ... err ... only really worked because of the dedication of our ... staff and ... err ... coercion of the other professionals involved!!" (Interviewee - Questionnaire Respondent 90, lines 168-171)

Several managers believed that establishing local information sharing protocols was essential in order to improve the effectiveness and efficiency of services delivered by the different agencies; for example:

"To me ... the information sharing agreements is crucial ... if not we're all duplicating work ... and ... err ... making unnecessary demands on our clients ... I ... err ... mean ... they have to go through the same questions with ... err ... the hospital ... Social Services ... then us." (Interviewee - Questionnaire Respondent 61, lines 121-125)

This particular manager also thought that the recently introduced single assessment process for older people, whereby a person's care needs are assessed thoroughly and accurately, but without procedures being unnecessarily duplicated by different agencies (Department of Health, 2002b), had the potential to improve the situation:

"The ... err ... new system ... single assessment process ... is ... err ... meant to help in that respect ... but ... err ... I certainly haven't seen much evidence of it yet ... maybe ... err ... it'll just take time to filter through ... I certainly hope so." (Interviewee - Questionnaire Respondent 61, lines 125-128)

One manager interviewed believed that the only real facilitator would be to have a joint budget across the NHS, social care and voluntary sectors to provide advice and support to visually impaired people:

"... shared budgets ... it's the only way we can ever hope to have a truly integrated service. By making us have a joint budget ... we will be forced to have common objectives ... reduce bureaucracy ... all the things that we ... err ... need to do!" (Interviewee - Questionnaire Respondent 86, lines 130-133)

Finally, several managers felt that the best approach was to focus on working together more closely on small-scale initiatives and by learning from successful ventures, instead of trying to enforce a series of large-scale changes. This is illustrated by the following quotes:

"... that may work better at a ... err ... local level ... rather than ... err ... going too big ... trying to do something nationally." (Interviewee - Questionnaire Respondent 46, lines 123-127)

"... it's more a case of better and more joined up working ... and ... err ... we shouldn't become obsessed about having a single service ... that may be ... err ... too ambitious ... and ... err ... as such ... actually prevent us from moving forward." (Interviewee - Questionnaire Respondent 61, lines 132-135)

"Err ... maybe it would be better to start off small ... looking at examples across the country where integrated working has worked ... and err ... see if that can be replicated elsewhere." (Interviewee - Questionnaire Respondent 4, lines 196-199)

Therefore, to conclude this section there is clearly potential for exploring further the concept of an "integrated information service" for visually impaired people in order to meet their health and social care information needs.

6.4.7 Research limitations

There are a few limitations associated with this study that should be noted. Firstly, this survey was of only 97 local society managers who were members of NALSVI, yet not all local societies are members of NALSVI. The high response rate (84%) achieved to the questionnaire, however, indicates that the findings are representative of NALSVI members. Local societies that are not members of NALSVI are difficult to identify and are generally very small organisations with limited resources and, therefore, were unlikely to have responded to the questionnaire anyway. Secondly, as noted previously, local societies for the blind and partially sighted differ considerably in terms of their size, outreach and range of services that they provide (Lomas, 2000). It is, therefore, not surprising that a range of responses were received. Finally, the approach sought to obtain the views of managers of local societies, but it may be that the views of other people working for the local societies would be different. Despite these potential limitations, this study has yielded some very interesting findings which have considerable implications for practice, as discussed below.

6.5 Conclusions and Implications

In conclusion, this first in-depth study of local societies for the blind and partially sighted has highlighted the important role local societies play in meeting the health and social care information needs of people with a visual impairment, in particular in terms of directing people to and finding information out on behalf of clients from a range of different information sources, including the Internet. The concept of an integrated information service for visually impaired people across the health, social care and voluntary sectors was generally well received by local society managers and suggests further work in this area is warranted. It is, therefore, helpful in this section to return to the questions posed at the start of this study to determine to what extent they have been answered.

6.5.1 What information do local societies provide to visually impaired people about health and social care matters?

It is clear from this survey that local societies provide a wide range of information to visually impaired people about health and social care matters, but the information provided mainly relates to aids, adaptations and equipment, and health and social care services available to visually impaired people. However, some local societies are also providing specific information about different eye conditions. Although, most societies appear to be using existing leaflets written by experts in the field and produced by national organisations, such as the RNIB, there is a need to disseminate this information to all local societies.

The type and amount of information provided by local societies appears to vary considerably from one society to another. This may be due to differences in the size of the society, availability of funding, and/or access to specialist expertise. However, it is clear that local societies have an important role to play in reinforcing information received by clients at the time of diagnosis.

6.5.2 Do the local societies provide the information that the interview participants expressed a need for?

On the whole, local societies do appear to be providing most of the information that the interview and audio diary study participants expressed a need for. However, as noted

above, the type of information provided varied considerably from one society to another. The emphasis of the information was also on aids, adaptations and equipment and services available to visually impaired people, only two of the areas that were identified in the interview study. This suggests that local societies need to work more closely with other agencies, such as the NHS and social care agencies, to ensure that all the information needs of visually impaired people are met. It was also surprisingly to find that the majority of information provided by local societies was verbal and only provided in alternative formats on request, and that very little of the information was targeted to particular groups of visually impaired people. There is clearly scope for improvement here, although it is acknowledged that are difficulties, particularly resource constraints, of doing so.

6.5.3 What information sources do local societies use to seek information for visually impaired people about health and social care matters?

It is apparent from this study that local societies use a variety of information sources in order to seek answers to clients' queries about health and social care matters. These range from national organisations, such as the RNIB, and health and social care professionals, to the Internet and the mass media. It was interesting, therefore, to find that NHS Direct was rarely used by the local society managers taking part in this survey. Even if the quality and quantity of information about eye conditions was improved on NHS Direct, the findings reported here seem to suggest that managers of local societies may still chose not to use it because of their own personal experience of using NHS Direct for other conditions. If NHS Direct is to be used as a means of communicating information about visual impairment, then there clearly needs to be further publicity about the information available to people with a visual impairment, their family and/or carers, as well as those working with visually impaired people.

6.5.4 How many local societies seek health and social care information for their clients via the Internet?

Of the 93% of local societies responding to this survey that had Internet access, three-quarters used the Internet to seek health and social care information for their clients via the Internet. Given the voluntary nature of many of the local societies this high proportion

is quite remarkable, but also indicates that managers of local societies are beginning to recognise the benefits, such as the speed of response, of using the Internet over traditional information sources on a variety of matters, including the availability and reviews of equipment for visually impaired people, and on the prognosis, diagnosis and treatment of rare eye conditions. It was also reassuring to find that several local society managers referred to the importance of establishing the reliability and validity of web sites. However, some of the responses indicated a need for more education in this area.

6.5.5 What do managers of local societies perceive to be the major barriers and facilitators to providing an integrated information service to visually impaired people across the health, social care and voluntary sectors?

Interestingly, there were mixed views and some confusion by the exact meaning of an “integrated information service” for visually impaired people, with several local society managers believing that they were already providing such a service. However, on the whole, the concept was well-received. In general, negative comments could be traced back to past experiences of failed joint working between local societies, the NHS and/or social care. The top three barriers to providing an integrated information service identified related to concerns about sharing personal information, conflicting priorities of different organisations, and budget constraints. There is, therefore, clearly a need for a more extensive training programme across the voluntary, NHS and social care sectors concerning the Data Protection Act and information sharing. However, managers taking part in this survey were able to identify ways of overcoming most of these barriers, as well as highlighted some key facilitators, such as developing local and/or regional visual impairment strategies, and actively involving visually impaired people in shaping services.

6.5.6 Implications for practice and future research

The implications for practice emerging from this exploratory survey are tentative, and require further validation from additional research. However, the following initial recommendations for practice and future research can be made. Firstly, local societies should attempt to target more of their information to specific groups of clients, instead of providing the same information to all clients. By doing so, they will meet individuals’ needs, rather than treating visually impaired people as a single homogenous group which

was identified as an issue within the interview and audio diary studies, as well as in the literature (*e.g.*, Beverley *et al.*, 2004). Secondly, staff at local societies should be trained in the use of the Internet and basic critical appraisal skills in order to respond to clients' queries about health and social care matters effectively and efficiently. Similarly, health, social care and voluntary sector staff need to be educated further about the Data Protection Act and sharing of information so that details about visually impaired people can be safely shared between different agencies. Finally, further work is required nationally, regionally and locally to improve the timing and format of information and to reduce the duplication of information provided to visually impaired people across the health, social care and voluntary sectors. This could form the basis of an "integrated information service" for visually impaired people.

There are several challenges to implementing these findings in practice, however, including the considerable differences in the size and resources of local societies; the major differences in the strategic direction and management of the NHS, social care and voluntary sector; as well as the fact that visual impairment is still not viewed as a major priority nationally, particularly within statutory organisations, such as the NHS and Social Care (Lovelock *et al.*, 1995; VISION 2020, 2006). These challenges must be overcome, however, to ensure that the health and social care information needs of people with visual impairments identified in the interview and audio diary studies are met. Visually impaired people have a key role to play in shaping future services which meet their needs. The next chapter considers how visually impaired people were involved in and informed the research presented in this thesis.

CHAPTER 7. INVOLVING VISUALLY IMPAIRED PEOPLE IN THE RESEARCH PROCESS

7.1 Introduction

The researcher believes passionately that the public should be engaged actively in research and service developments relating to their health and social care. Not only is this considered ethically right (Boote *et al.*, 2002), but the involvement of the public in research is thought to result in research that is more relevant, reliable and likely to be used (Chalmers, 1995; NHS Executive, 1999). Despite major drives by the English government to encourage public involvement, there are surprisingly few examples of rigorous evaluations of public involvement. This is supported by literature emerging since the conception of this research (*e.g.*, Boote *et al.*, 2006). In addition, at the start of this research, as highlighted in Section 3.9.7, there were only two published studies that had involved visually impaired people in the research process, although it is acknowledged that there may be more within the grey literature.

An important and novel feature of this thesis was, therefore, the involvement of people with visual impairments in the design of the research, and the subsequent evaluation of the impact their involvement has had on both the design and outcomes of the research. This chapter describes how people with visual impairments were involved throughout the research and identifies where changes were made, either directly or indirectly, in response to their suggestions. The chapter concludes by making some tentative recommendations about how visually impaired people can be involved more effectively in the planning and conduct of future research in this field.

7.2 Aims and Objectives

The overall aim of this part of the research was to explore how involving visually impaired people in this research could contribute to public involvement research. There were, therefore, two specific objectives:

1. To determine what impact, if any, actively involving visually impaired people in this research had on the overall research design and outcomes.
2. To identify ways in which visually impaired people can become involved more effectively in the planning and conduct of future research in this field.

7.3 Methods

A mixed consultative and collaborative approach to user involvement (Hanley *et al.*, 2004) was adopted, as discussed in Section 3.9. At the start of the research, involvement was mainly at a consultative level, that is, people with visual impairments were asked their thoughts on the overall research design. However, as the research progressed, their involvement became more collaborative for some visually impaired people, that is, there was a more active and ongoing partnership between the researcher and a small sample of visually impaired people. Although the researcher considered adopting a user-led approach, whereby visually impaired people would have designed, undertaken and disseminated the results of the research, it was decided that this approach was not appropriate for the researcher to attain an academic qualification. Further details about the specific approaches adopted are provided below.

7.3.1 Consultation

At the start of the research, in February 2003, the researcher approached the Chairs of three local visual impairment support groups in Sheffield in order to attend one of their meetings. Two of these groups were specifically targeted at particular groups of visually impaired people (younger people with a visual impairment and people with age-related macular degeneration), whilst the other group was generic, comprising people of all ages with different visual impairments.

At these meetings, the researcher briefly outlined the purpose of the discussion, the background to the research, the proposed research questions and methods, and then facilitated discussions on four main topics: preferred terminology in terms of visual impairment; experiences of health information; the research questions; and the research methods. Although the main purpose of the discussion was to gauge opinions about the proposed research questions and methods, the first two topics were designed to

encourage people to participate and to focus on the specific research area. Doing so also enabled the researcher to gain a better understanding of the issues facing people with a visual impairment.

Notes were made both during and immediately after the discussions. However, the discussions were not tape recorded and transcribed. This was because the consultation exercise did not constitute a formal part of the research study and the researcher did not want the people attending the support groups to feel that they were used as research 'subjects'; instead they were active participants (Hanley *et al.*, 2004).

7.3.2 Collaboration

Another strand of public involvement in this research was collaboration with several visually impaired 'advisors'. Five visually impaired people were identified, via the local visual impairment support groups and the INVOLVE web site, to act as advisors to this research study. These people were provided, in their preferred format, with further details about the study and a 'job description', reproduced in Appendix L, outlining the principal responsibilities of the advisor. The advisors were notified at the start that, due to the nature of the funding of the research, their role was voluntary and unpaid, although any expenses (*e.g.*, travel, stationery, telephone charges, *etc.*) incurred as a result of participating in the study would be reimbursed. The advisors were consulted on a regular basis (at least every four months), either face-to-face, over the telephone, or by email. They were consulted on eight areas of the research, as well as were sent regular updates on the progress of the research and were interviewed twice. The specific areas of consultation were:

1. The background to the research and original research questions and methods.
2. An overview of the plans for the interview study, including the draft interview topic guide.
3. The initial findings of the interview study.
4. An overview of the proposed audio diary study, including the draft interview topic guide.
5. The initial findings of the audio diary study.
6. Proposals for the next and final stage of the research.
7. The proposed survey of managers of local societies for the blind and partially sighted.

8. The initial findings of the local societies survey.

Initially three, although latterly two, of these advisors contributed to the evaluation of user involvement in this research by being interviewed at the start of their involvement in the summer of 2003, and then again at the end of the research in summer 2007. These advisors were selected because of the extent to which they met the person specification outlined in the advisor 'job description' (Appendix L). For instance, all three of the chosen advisors possessed a visual impairment, were willing and able to familiarise themselves with new terminology, expressed an interest in 'user involvement' in research, had good communication skills, and had links with networks and/ or organisations serving visually impaired people.

Each advisor was provided with an information sheet relating to the interviews in their preferred format, shown in Appendix M. At the start of each interview, it was checked that the advisor had received and read the information sheet, *i.e.*, they were adequately informed about the study. The interviewer also reiterated that participation in the interview was voluntary and that the advisor was free to withdraw at any time, without giving a reason.

The advisors were given the choice of the format and date of the interview. Initially, two advisors elected to have a telephone interview, whilst one opted for a face-to-face interview at the University. All the follow-up interviews were conducted by telephone. The interviews were tape-recorded, with permission from the advisor, using a Sanyo Compact Cassette Recorder (TRC-1148).

A topic guide was used to structure the interviews (refer to Appendix N and Appendix O). Due to the highly specialised nature of these interviews, it was not possible to pilot the schedule on an equivalent group of people. However, the schedule was tested with a totally sighted volunteer to check its face and content validity. The initial interviews covered the advisors' reasons for agreeing to be involved in the study, their perceived role in the research and what they hoped to gain from being involved, whether they had any outstanding training and development needs, and their understanding of the phrase 'consumer involvement'. It is important to note here the use of the term 'consumer involvement' rather than 'public involvement'. This is because at the time of conducting

the interviews, 'consumer involvement' was the preferred terminology in the field, as described in Section 3.9.2. The follow-up interviews covered the advisors' actual role in the research and how this compared with their original expectations, whether they were always clear about their involvement in the research, what they had gained from being involved and how they had contributed to the research, as well as how they thought their involvement could have been improved.

Within two weeks of each interview, the tape recorded interview data were transcribed into *Microsoft® Word*. A simple manual thematic analysis, drawing on some of the systematic steps of framework analysis (Ritchie and Spencer, 1994) was undertaken to identify key themes and sub-themes. A short briefing based on the interviews was shared with the advisors for them to verify the findings.

7.3.3 Researcher's reflective diary

The final component of this part of the research was the lead researcher keeping a personal reflective diary in *Microsoft® Word* throughout the entire duration of the study where she documented any noteworthy issues associated with the public involvement aspects of the research, such as successes and challenges. Adopting this approach has helped to reduce recall bias and increase objectivity by recording real time thoughts and experiences. This diary was analysed at the end of the research using a simple manual thematic analysis.

7.4 Findings

7.4.1 Consultation

In total 31 people attended the three local visual impairment support groups. The majority, estimated to be 28, of attendees had some form of visual impairment. The other people attending the groups were assumed to be either partners and/or carers. The sex ratio differed considerably between the groups: one group was only attended by men, there were equal numbers of men and women in another group (including one sighted female carer), while in the third group the men were outnumbered 2:1 by women, although this did include two sighted female partners. Across all three groups, it was estimated that over 80% were 65 years or older. In addition, several were thought to be over the age of 80

years. All of the people with a visual impairment attending the groups were registered as either blind or partially sighted. It emerged that the length of impairment varied considerably from several weeks to more than 20 years. One group consisted entirely of people with AMD, although it was noted that several people in this group also had other eye conditions, such as glaucoma and cataract. The causes of the visual impairment in the other two groups were less clear. It was apparent that several people attending the groups also had one or more additional health conditions, such as hearing impairment, diabetes, breathing problems and/or mobility problems. The characteristics of the attendees were, therefore, similar to that in the visual impairment in the general population (RNIB, 1998b).

7.4.1.1 Preferred terminology

The issue of preferred terminology in terms of 'visual impairment' was only explicitly discussed in the group mainly comprising people with AMD. Of the various terms suggested by both the researcher and other members of the group (*e.g.*, blind, partially sighted, sight impaired, visually impaired, visually handicapped, visually disabled, etc), the consensus of the group was for the phrase 'people with a visual impairment'. It was felt that this phrase was the most understandable to the general public, as well as acceptable to people with a visual impairment. The phrase 'people with a visual impairment' was preferred over the phrase 'visually impaired people' as the former recognised people as being individuals first, rather than as being impaired. Interestingly, in the other two groups, people referred to themselves as being 'visually impaired'. Other authors have come to a similar conclusion; for example, Brophy and Craven (1999) opted to use the phrase 'blind and visually impaired' throughout their research studies. However, Abaglo and Downing (1990) found that there was no statistically significant difference in the preference amongst visually impaired people for the two terms. Bolt (2003) and the Department of Health (2007) have recently explored this terminology in more detail. Interestingly, the Department of Health now advocate the use of the word 'sight impaired' and 'severely sight impaired' for 'partially sighted' and 'blind' respectively. It would have been interesting to have discussed these terms with the support group attendees. In response to these discussions, however, the term 'people with a visual impairment' has been used predominantly throughout this thesis.

7.4.1.2 Experiences of health information

All three groups emphasised the need to adopt a broader definition of 'health' to incorporate social care issues as well, because the distinction between the two was often unclear and the distinction did not matter to them as patients and/or service users. This finding is also reflected in the literature; for example, Lewis (2001) found that the artificial separation between health and social care can be divisive, not only for service users, but also for professionals. As a result of these discussions, the original research questions were, therefore, changed to incorporate social care information as well as health information. Group members mentioned that they had received or sought information about health and social care issues from a variety of sources, including Social Services, General Practitioners, the low vision clinic at the hospital, the local society for the blind and partially sighted, local support groups, and friends and family.

Across all the groups, it was clear that the health and social care information needs varied between individuals, for example, it emerged people living alone had different needs to people who were living with other people. In addition to the information issues already identified in the literature review (*e.g.*, concerning drug labels, appointment letters and test results), the groups identified several additional problematic areas concerning health and social care information. These included the provision of information at the time of diagnosis, finding information about allowances, benefits and grants, such as disability living allowance, the flow of information between health professionals and between health and social care, and confusion about where to seek appropriate information. Interestingly two of the groups specifically mentioned accessing health and social care information on the Internet. While one group, consisting mainly of men in their 30s and 40s, was keen to see this method of information delivery developed further, another group, comprising people aged over 60 years of age, was not. Two of the groups concluded that things had improved considerably and that those who had registered during the last few years had received more information and support, particularly from the hospital low vision clinic.

7.4.1.3 The research questions

All three groups seemed to be genuinely interested in the proposed research and agreed that the study was worth conducting. Although the format of information was considered important, other issues, particularly the content, timing and support structures available,

also needed to be considered. As noted previously, it became clear that the scope of the research should be expanded to include social care, as well as health, information because it was often difficult to distinguish between the two. It also emerged that the flow of information among health professionals and between health and social care was an important area that warranted further investigation. There was a general consensus that the information needs varied considerably between individuals, for example, in terms of age, type of visual impairment, degree of visual impairment, length of visual impairment, presence of other health conditions, and access to support structures, such as friends, family and carers. It was suggested that it would be more appropriate to look in-depth at one (or possibly two) groups of people with a visual impairment, for example, people with AMD and people who were congenitally blind, rather than try to include all visually impaired people. As a result of these comments, the interview study, described in Chapter 4, involved two different groups of visually impaired people.

7.4.1.4 The research methods

Across all three groups, there was a clear preference for the first stage of the research to consist of individual face-to-face interviews with people with a visual impairment, rather than focus groups with several visually impaired people. Some people indicated that they would feel less inhibited and more at ease in an individual rather than a group situation. Conducting individual interviews with visually impaired people, rather than focus groups, would also enable the researcher to explore the varying information needs of participants in more depth. Face-to-face interviews were favoured to telephone interviews, although it was agreed that the latter approach might be acceptable for people who did not live locally. This is similar to the findings of another study: Carrick *et al.* (2001) abandoned focus groups in favour of individual interviews at the request of the participants. In contrast, Kerruish (1995) abandoned individual interviews in favour of groups in order to be less oppressive. The design of the study was, therefore, changed, as described in Chapter 4, so that it comprised individual face-to-face interviews with people with two types of visual impairment.

7.4.2 Collaboration

As noted previously, all three advisors originally identified as being most appropriate to be interviewed at the start of the evaluation agreed to take part. However, only two advisors were interviewed at the end of this research. This was because the remaining advisor had moved house and had not left forwarding contact details. In hindsight, this was one of the flaws in only consulting with the advisors three or four times a year.

7.4.2.1 Characteristics of the participants

Two of the advisors were male (aged 39 years and 76 years respectively) and one was female (aged 70 years). All three advisors lived in Yorkshire. One of the advisors was married, whilst the other two lived alone. At the time of the interview, one of the advisors was working full-time, whilst the other two were retired. The cause of visual impairment varied between advisors: one had glaucoma, one AMD and one retinitis pigmentosa. All three advisors had experienced sight problems for at least twenty years and were registered either blind (two advisors) or partially sighted (one advisor). One advisor was first diagnosed as having a visual impairment at the age of seven when he was placed on the partially sighted register; he was subsequently registered as blind at the age of 15. Another had experienced sight problems since the 1970s, being registered blind in 1981. The remaining advisor had noticed a deterioration in his vision as a result of AMD over the previous three years, although he had previously (over twenty years ago) had problems with a detached retina.

7.4.2.2 Characteristics of the interviews

The first interviews lasted for a median of 31 minutes, with a range of 19 to 50 minutes. This corresponded to a mean of 3,680 transcribed words. In contrast, the follow-up interviews were considerably shorter with a mean of 15 minutes, which corresponded to a mean of 1,205 transcribed words.

7.4.2.3 Interview themes

Six main themes were identified across the two sets of interviews. These are presented diagrammatically in Figure 8. Most of the themes reflected specific interview questions

(refer to Appendix N), such as the advisors' understanding of the terminology relating to 'public involvement'; their reasons for agreeing to take part in the study; their perceived and actual role in and contributions to the research; the benefits of their involvement; and suggestions for how their involvement could have been improved. However, one theme was unexpected, *i.e.*, the advisor's own personal experience of having a visual impairment. It should be evident that from Figure 8 that the advisors' personal experiences of having a visual impairment was at the heart of all the interview themes, and that all the themes were closely linked, so, for example, the reasons for the advisor agreeing to be an advisor affected their role in, and contribution to, the research, and this subsequently influenced their suggestions for improving involvement in the future.

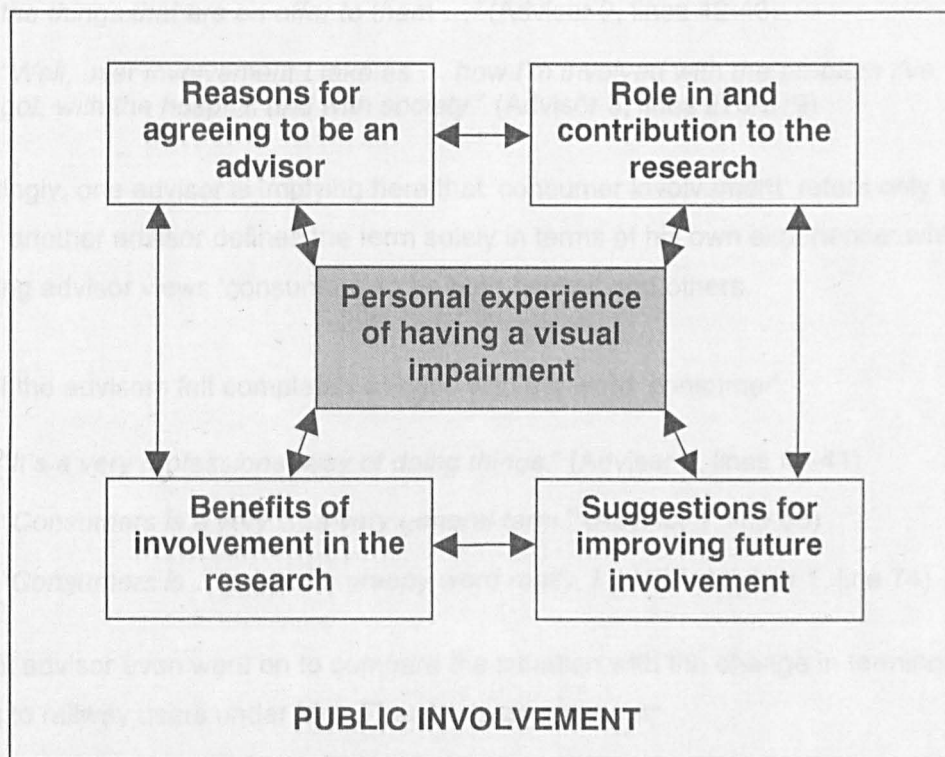


Figure 8. Diagrammatic representation of the six themes emerging from the advisor interviews. Personal experience was central to all themes, and public involvement encompassed all themes.

A. Public involvement

As noted earlier, at the time of conducting the initial interviews, the phrase 'consumer involvement' was commonly used in the literature and, therefore, this terminology was used. All three advisors appeared to have a good understanding of the phrase 'consumer involvement' and the complexities associated with it:

"... I suppose it can mean different things in different contexts really ..."
(Advisor 1, line 45)

'Consumer involvement' was defined in the following manner by each of the advisors:

"... you are obviously talking about people who use the services you are looking at" (Advisor 1, lines 46-47)

"... basically, all you want to know is how I, or another person, uses the ... the things that are on offer to them ..." (Advisor 2, lines 42-43)

"Well, user involvement I take as ... how I'm involved with the problem I've got, with the hospital and with society." (Advisor 3, lines 278-279)

Interestingly, one advisor is implying here that 'consumer involvement' refers only to 'other' people; another advisor defines the term solely in terms of his own experience; whilst the remaining advisor views 'consumers' to be both himself and others.

None of the advisors felt completely at ease with the word 'consumer':

"It's a very professional way of doing things." (Advisor 2, lines 40-41)

"Consumers is a very ... a very general term." (Advisor 1, line 58)

"Consumers is ... a bit of a creepy word really, I think." (Advisor 1, line 74)

This last advisor even went on to compare the situation with the change in terminology relating to railway users under Mrs. Thatcher's government:

"We became customers, instead of passengers, on the railway." (Advisor 1, line 58)

However, there was no consensus over a preferred term and an acknowledgement that:

"No matter what word you look up it's wrong." (Advisor 1, line 70)

Having said that, one advisor clearly expressed a preference for the word 'user':

"Users is a lovely word ... I mean user may be the most neutral if it weren't for the links with drug abuse, and I don't think most people will make that connection, do you?" (Advisor 1, lines 71-72)

The same advisor also proposed the term 'consultant' as an alternative. This idea was initially dismissed due to associations with hospital consultants in the NHS. However, the word 'consultant' is defined by the Oxford English Dictionary as a, '*person consulted for professional advice, esp. in branch of medicine*', which certainly seems appropriate. It is, therefore, recommended that the term 'consultant' is considered for use in future research studies.

Two advisors felt that the term 'client' was inappropriate:

"Clients they sometimes say ... which implies a certain subservience to the service, doesn't it?" (Advisor 1, lines 62-63)

"... I don't like ... the word client because that's what I am to my solicitor, not my friend." (Advisor 2, lines 53-54)

These findings relating to the problematic terminology surrounding 'consumer involvement' certainly support the messages reported elsewhere (e.g., Boote *et al.*, 2002). In response to the advisors' comments about the word 'consumer' and the emerging changes in the national literature on public involvement, the advisors' job title was changed from 'consumer research advisor' to 'advisor'.

B. The advisors' personal experiences of having a visual impairment

Although the advisors were not specifically asked to give examples of the problems they encountered in relation to their visual impairment, several instances emerged during the course of the interviews. On the whole, the advisors demonstrated positive strategies for dealing with their own visual impairment, for example:

"So I'm probably lucky in that way that I have got something to occupy my time and not sit worrying about problems, you know." (Advisor 3, lines 194-195)

However, it was also evident, particularly in the case of one advisor, that she reluctantly accepted that her visual impairment meant that she was disadvantaged in certain respects:

"... I have a certain fatalism, that I have to recognise on a daily basis that there are certain things that I would ideally like that I'm not going to get."
(Advisor 1, lines 119-120)

Referring to the problems she encountered trying to read a health bulletin on dietary supplements, she noted that:

"Realistically speaking I'm not going to find somebody who's going to read this literature to me and, even if they did, and that's probably not, they would only read it once, whereas if one could actually read oneself you would go back and check facts. You quite often, you have to make do with one reading of things, but quite often it's alright I mean you can get someone to read, say the dosage on a pill bottle to you, something short, but anything which is a little bit more thoughtful and requires a little bit more consideration, well, you're probably not going to get it and this does puts us at a considerable disadvantage ... One of a number of rather niggling irritations which, at the end of the day, means you are less well-informed than someone who is able to read." (Advisor 1, lines 126-133, 140-142)

The treatment one of the advisors was currently receiving for his visual impairment, photodynamic therapy (PDT), was at the forefront of his mind. The following quote demonstrates the advisor's own awareness of his eye condition and prognosis:

"It's an illness ... well, they call it macular degeneration, it gradually deteriorates, until you virtually ... I don't think you go completely blind, but you're not far off. And so I thought it's worth a try, even if it's got worse I've taken the opportunity which is quite unique and very very expensive. And I thought well it must be worth the while for the hospital board to be giving this treatment at this price, you know, this expense, if they didn't think there was some useful results from it." (Advisor 3, lines 95-101)

It is interesting to note that two of the advisors, referring to being unable to read a health bulletin and having problems taking a shower, implied that they were at fault for not taking things further:

"No, I suppose again, I suppose this is perhaps, this is partly my fault. I mean, maybe, we should make the move and say could you possibly provide this for me on tape, or something like that." (Advisor 1, lines 135-137)

"It's one of those things that's not urgent and something I can think about, you know." (Advisor 3, lines 341-342)

C. Reasons for agreeing to be an advisor

The reasons for agreeing to be an advisor varied between individuals. However, the major reasons given at the start of the research could be classified under the following five headings: to offer advice in the form of knowledge, contacts and direction; altruistic reasons; a desire to be involved in research; a belief that research should involve users; and 'practical' reasons. Unsurprisingly, given the four years that had passed, the advisors found it difficult to remember at the follow-up interviews why they had agreed to take part:

"I can't remember exactly what I ... err ... said ... err ... back then ... it was ... err ... a long ... time ago now ... wasn't it?" (Advisor 1, lines 6-7)

However, after some thought, the reasons given by the advisors were remarkably similar to those originally stated.

Offering advice in the form of knowledge, contacts and direction was the most commonly cited reason, being mentioned by all three advisors. This is aptly illustrated by the following quotes taken from the transcript of one of the advisor interviews:

"... hopefully some of my knowledge and the contacts I've got I can go away and talk to and ask how did you find out this ... whatever ... and I can hopefully relate back to you what other people who won't necessarily feel comfortable being interviewed or answering questions about their personal bits ... because they are embarrassed or something ... I may be able to act as go-between in them sort of circumstances." (Advisor 2, lines 23-27)

"... to point you in the right direction ..." (Advisor 2, line 33)

"... hopefully to give you another angle of looking at problems and circumstances ... sometimes playing devil's advocate!" (Advisor 2, lines 36-37)

During the follow-up interview, one advisor focused on her knowledge and experience, both about visual impairment and research:

"that was nice ... to be ... well ... in some ways ... appreciated ... for ... err ... my knowledge ... experience ... previous involvement in research." (Advisor 1, lines 9-10)

This quote also indicates that the advisor felt valued, and that her knowledge and experience had proved useful to the research.

It was reassuring to find that the most commonly cited reason for the advisors agreeing to be involved (to offer advice in the form of knowledge, contacts and direction), corresponded well with the researcher's original intentions and the job description. It could be argued that, by receiving the job description prior to the interview, this affected the advisors' responses. However, as noted below, the advisors found the job description helpful in clarifying what was expected from them in the research study. It also meant that the individuals were fully informed about their role in the research before they agreed to take part.

In addition to agreeing to be an advisor for personal reasons, two of the advisors also alluded to more altruistic reasons, expressing an interest in the needs of visually impaired people as a whole, as well as indicating their willingness to help with the research, particularly the researcher. For example:

"... I am interested both ... from my own point of view but also more generally in the problems of visually impaired people and the solutions that are found to them." (Advisor 1, lines 25-26)

"And ... and I like helping people out!" (Advisor 2, lines 27-28)

This was reiterated in the follow-up interviews:

"I hoped that ... err ... it would be ... err ... good to help others ... other blind and partially sighted people ... as well as ... err ... you ... yourself." (Advisor 1, lines 10-12)

All three advisors seemed genuinely interested in the research study and the value of research, as illustrated by the following quote:

"Because if people don't ask questions, they don't find out the answers." (Advisor 2, lines 22-23)

One advisor had been involved in research before, and, therefore, was interested to build upon her knowledge, whereas another advisor expressed a desire to be part of a research study:

"I've never been involved in market research type things and, ok, this isn't exactly market research but in a way you are researching what people want ... and I can actually say, no I know she's actually asked people, because I was one of them ... I can actually relate it to ... I've actually had a personal input in this ..." (Advisor 2, lines 74-78)

This advisor elaborated on this aspect in the follow-up interview, where it emerged one of his main aims of being involved was to try and make sure the research was not just an academic exercise:

"... I ... err ... wanted to make sure ... it ... was ... practical ... do you know what I mean? I ... err ... didn't want your research ... err ... to be ... too distant ... not ... err ... linked to reality ... to ... err ... practice. I ... err ... think we talked about this before ... all these people at universities doing research ... perhaps all very good ... but ... err ... what's the point if ... err ... nothing's going to change at the end." (Advisor 2, lines 10-15)

It was evident that two of the advisors had specifically made the decision to take part in the research, because they believed that users of the research should be actively involved in the research process:

"... because I believe that pieces of work and research like this should involve the people that the research is about." (Advisor 2, lines 19-20)

Finally, the advisors gave several other 'practical' reasons for agreeing to be an advisor to the study. For example, one advisor agreed because she was asked:

"Firstly because I was approached ..." (Advisor 1, line 24)

She also thought that it would not take up too much time, although interestingly she looked for clarification about this:

"I mean, on the other hand, I-I don't envisage it to be too onerous. I hope it isn't?" (Advisor 1, line 29)

D. The advisors' role in and contribution to the research

At the start of the research, all three advisors appeared to have a good grasp of their role in the research, what was expected from them, and what they could realistically expect from their involvement in the study. The job description (Appendix L) proved to be a useful document in this respect, with two advisors specifically mentioning in the initial interviews

that they had referred back to it before being interviewed. One advisor even ran through the contents of the job description in the initial interview, thereby demonstrating a high level of familiarity with the document. All of the advisors felt the job description was clearly written and accessible, and did not require any changes. One advisor did note, however, that the document should not be *“set in concrete”* (Advisor 1, line 89) and may be altered during the course of the research. It was interesting, therefore, to find in the follow-up interviews that neither of the advisors had consulted the job description again:

“Oh ... I'd completely forgotten about that.” (Advisor 1, lines 45-47)

“No, sorry, I haven't. I haven't needed to though ... I read it at the start ... and ... err ... that's when I needed it.” (Advisor 2, lines 40-41)

Knowing that the job description existed and could be referred back to was considered important by the advisors, however:

“Maybe if you ... err ... had started asking me to do ... I don't know ... all sorts of ... erm ... strange things ... then ... err ... maybe I'd have gone back to it and said ... ‘where's that on here?’” (Advisor 2, lines 41-43)

During the initial interviews, the advisors were asked if they felt that they had any outstanding needs in relation to the research. All three advisors felt that they were adequately informed, but that they would not hesitate to contact the researcher if they had any queries:

“... if there was anything, you're basically at the end of a 'phone ...”
(Advisor 2, line 127)

At the follow-up interviews it appeared that the advisors' actual role in the research was very similar to what the advisors had originally envisaged; for example:

“Mmm ... honestly ... it has really just been as an advisor ... maybe a friend ...” (Advisor 2, line 19)

“... you explained at the start ... that my role would be to ... err ... advise ... rather than do.” (Advisor 1, lines 39-40)

The advisors' actual role in the research seemed to mimic some of their original reasons for agreeing to take part, in particular in terms of offering advice in the form of knowledge, contacts and direction:

"I've just been able to point you in a new ... or different ... direction sometimes ... maybe give a few reasons ... an insight into how things operate in practice ... give you more of an awareness and understanding." (Advisor 1, lines 61-63)

"... helped to ... err ... persuade others of the importance of your research ..." (Advisor 2, lines 57-58)

However, rather worryingly from the researcher's point of view, the advisors in both the initial and follow-up interviews seemed to feel that their role was peripheral:

"My involvement is peripheral really. You're the one who's doing all the work. It's your time that's being used up." (Advisor 1, lines 164-165)

"... I ... err ... don't think I've had a major role to play ... just on the edge ... err ... looking in. I don't know whether that was the intention ... but ... err ... that's how it worked out." (Advisor 2, lines 20-22)

It also emerged in the follow-up interviews that the advisors involvement in the research was actually less than they had expected and had hoped for:

"I suppose I thought it would have been more onerous ..." (Advisor 1, line 21)

"... I suppose I never really felt completely engaged with the research ... more of an ... err ... outsider looking in ..." (Advisor 1, lines 26-27)

One advisor even thought that the researcher refrained from asking for more help because she did not want to impose on his time:

"Maybe sometimes you didn't want to ask for more ... err ... help because you thought it was a burden on me ..." (Advisor 2, lines 29-31)

He also thought that he was possibly at fault for not approaching me, rather than always relying on me contacting him first:

"I guess I could have been ... err ... better at coming forward with ideas." (Advisor 2, lines 36-37)

Both advisors would have liked to have been more involved in actually undertaking some of the research themselves, although they acknowledged the limitations of undertaking Ph.D. research:

"... I suppose ... it's just I might have liked to have done more doing! I understand though the constraints of your research ... err ... and was happy to go along with this." (Advisor 1, lines 40-42)

On the one hand, these kinds of comments suggest that the advisors did not think that their contribution was valued. However, on the other hand, the advisors seemed quite content with their level of involvement:

"not that I am ... err ... complaining ... I probably wouldn't have wanted to have been more involved ..." (Advisor 1, lines 20-21)

In response to the question in the initial interviews, 'what do you hope to be able to contribute to this research study?', all three advisors emphasised their role as information providers. This was perhaps most aptly demonstrated by one advisor who was currently undergoing treatment for AMD:

"Well, I'm hoping with the PDT treatment, that will be very useful, and with my association with the Macular Society and [the local society]. You know, I hear things and it might be information that would be useful to you." (Advisor 3, lines 397-398)

However, the source of this information varied between advisors, from links with organisations and societies representing visually impaired people; from direct experience of having a visual impairment; and from previous research experience. Links with organisations and societies representing visually impaired people were the most emphasised source of information and was particularly apparent with the advisors based in Sheffield who were involved with voluntary organisations and groups, such as the local society for the blind and Macular Disease Society:

"... the contacts that I have with other people in the community ... other professionals ..." (Advisor 2, lines 92-93)

"Then, of course I'm on the committee of the Macular Society in Sheffield, so there are things that come out of that which could be useful ..." (Advisor 3, lines 188-189)

Unsurprisingly, all three advisors mentioned that they could contribute to the research in terms of their personal experiences of having a visual impairment:

"... some of my own personal knowledge ... and ... wants of what information I would like and how I would like to access it and where ..." (Advisor 2, lines 91-92)

"I mean this PDT treatment, for example, is really very new. And so, it's something ... if something happens to me, at least I can pass it on to you and you can make a note of it." (Advisor 3, lines 291-293)

One advisor felt that she could contribute to the research design, having been involved in research before:

"... also having thought quite deeply about the problem in connection with our research, I hope I may be able to make some useful comments on your findings." (Advisor 1, lines 39-40)

In particular, during the course of the interview, she highlighted the problems associated with implementing the research findings:

"A lot of research is carried out and, I think, the implementation is a tricky ... a tricky area ... there aren't clear links through to policy makers or anything like that, are there?" (Advisor 1, lines 109-111)

She continued to offer advice on how to overcome this hurdle:

"Because a lot of very careful and continuous research ... may be very praise worthy, but people don't read these days ... they don't read ... and erm ... you really need something to grab people with, don't you?" (Advisor 1, lines 113-115)

Another advisor wanted to ensure that the approach I was adopting was appropriate and acceptable to the people taking part:

"... it's being sensitive to the people's needs ... which I know you would be ... but ... but it's just sometimes people just want to go and hide and not want to even admit that they're going to lose their sight ... and because I wouldn't know how to tackle it and I was wondering whether you would ..." (Advisor 2, lines 114-117)

E. The benefits of involvement in the research to the advisors

All three advisors were slightly taken aback by the question in the initial interviews relating to what they hoped to gain from being involved in the research study, possibly suggesting that they had not considered this aspect of their involvement before:

"Well, I wasn't really expecting much at all from you ..." (Advisor 3, line 353)

Having had chance to think about this question, the advisors gave very different answers, perhaps reflecting their varied backgrounds. The advisor who had been involved in another study previously was most interested in learning the findings of this research; whilst the advisor who had experienced a visual impairment since early childhood was looking forward to actually being involved in a research study and learning about the research process. Finally, the advisor who was currently undergoing a new treatment for his visual impairment thought he would benefit from being able to share his experiences with someone who was interested:

"... it might be useful for me to be able to talk to you about it, because it's giving you all the information I have without worrying about boring someone to death ..." (Advisor 3, lines 355-356)

"So it's useful to speak to you ... and I don't really expect much back in return ... apart from you're a good listener ..." (Advisor 3, lines 362-363)

Although not in response to this particular question, one advisor identified the benefits of being able to share information both ways, that is, both between himself and the researcher and between himself and others:

"... to try and liaise and pass bits of information both ways, backwards and forwards ... then I'm in control of both sides of the conversation, aren't I?" (Advisor 2, lines 93-96)

It was, therefore, disappointing to find in the follow-up interviews that the advisors did not feel they had benefited much from their involvement in the research:

"Mmm ... again, if I'm honest ... probably not very much." (Advisor 1, lines 51-52)

However, it was apparent that the advisors were genuinely happy to act as advisors and seemed to enjoy the social interaction:

"... I'm quite happy ... to have a little chat from time to time and, you know, say what I have to say, if it's any use?" (Advisor 1, lines 165-166)

"... I'm happy to come here and have cups of tea." (Advisor 2, line 125)

One advisor was also particularly interested in following the personal progress of the researcher:

"It's ... err ... been good to be involved ... to have chats with you ... to monitor your progress ... I suppose I've been more interested in that ... seeing you stick with it all these years ... rather than ... err ... I suppose the rest of it." (Advisor 1, lines 52-53)

F. Suggestions for improvement

After initial hesitation, both advisors were able to make some suggestions about how their involvement in the research could have been improved. The fact that the advisors felt they were able to make these suggestions demonstrated the good relationship that had developed between the researcher and the advisors during the course of the research. It also showed the advisors' ability to critically reflect on their own experience, an essential part of their role as an advisor. Both advisors did note, however, that their involvement had been a pleasant experience, and they hoped that their comments would be viewed constructively; for example:

"I feel like I'm being negative when I don't mean to be." (Advisor 2, lines 79-80)

Specific areas which the advisors felt could have been improved included the frequency and method of consultation; the ability to influence the research; involvement in actually undertaking some research; and further consultation on the research findings. In terms of frequency of consultation, it was clear that consulting the advisors every three to four months was probably insufficient, particularly as the advisors found it difficult to keep track of the progress of the research. More regular, perhaps monthly, updates were proposed. This is illustrated by the following quotes:

"I suppose more frequent contact would have been helpful ... once every few months probably isn't enough ..." (Advisor 1, lines 68-69)

"It was also easy to ... err ... forget ... I don't mean that in a bad way ... but you've been doing this research for ... well ... so long now ... that it was sometimes difficult to remember where you were up to ..." (Advisor 2, lines 64-67)

In terms of the method of consultation, although the majority of contact was made via email and over the telephone, it was clear that at least one of the advisors would have preferred more face-to-face contact. It was also suggested that meetings of all the advisors would have proved beneficial at certain stages in the research process. For example:

"... it would ... err ... also have been good to have met face-to-face ..."
(Advisor 1, lines 69-70)

"It would ... err ... also have been interesting to meet your other advisors ... maybe every 6 months for us to have a ... err ... big get together ... meeting ... share ideas ..." (Advisor 2, lines 70-72)

One advisor in particular expressed concern about actually being able to influence the course of the research, although he did acknowledge that, on the whole, he was very happy with the proposals.

"Err ... also, sometimes it was ... err ... difficult to influence what you were going to do ... maybe because of the timing ... although that may have been my fault ... you know ... if I really didn't think what you were doing was a good idea ... not that I did ... but if I did ... I'm not sure it would have been possible to say ... err ... 'No, stop!' I'm probably wrong there, but ... err ... I know the ... err ... constraints of academia!" (Advisor 2, lines 73-79)

This is of particular concern to the researcher because one of the intended roles of the advisors was to challenge approaches. It is possible, however, that, as noted previously, the advisors were aware of the limitations of undertaking Ph.D. research and, therefore, thought that their ability to influence the overall design was somewhat constrained. If this is the case, then this warrants further explanation to users at the start of future Ph.D. studies.

The advisors also expressed a desire to be consulted more on the findings of the research. For example:

"I guess ... at times it was ... err ... very front ended ... by which I ... err ... mean ... I was often asked ... consulted when you were thinking of doing something ... less so when you ... err ... had some findings." (Advisor 2, lines 84-87)

Although the findings of each of the individual studies were shared with the advisors, in hindsight this was mainly for information and verification purposes and again the advisors may not have realised their ability to influence the interpretation of the findings. Also, at the time of undertaking the follow-up interviews a summary of the overall findings of the research had not been shared with the advisors and, therefore, it was not surprising that one advisor commented on the following:

"I suppose what I'm getting at is ... err ... if someone asks me what are the key messages from your research ... err ... I'm not ... err ... sure ... at least at this stage ... I ... err ... would be able to tell them." (Advisor 2, lines 87-89)

It was clear, as noted earlier on in this chapter, that ideally the advisors would have liked to have been more involved in the research, including actually undertaking some of the research, in particular conducting some of the interviews.

"Mmm ... perhaps by being more involved ... I understood that wasn't my role ... but ... err ... I would have liked to have ... maybe accompanied you on some of ... err ... your interviews ... maybe undertaken some myself." (Advisor 2, lines 62-64)

This idea was originally dismissed because it was thought that this did not meet with the requirements of undertaking a Ph.D. However, after further investigation, it would have been possible for the advisors to have undertaken a few of the interviews as long as this was clearly acknowledged. Future researchers should, therefore, bear this in mind.

Finally, one advisor commented:

"I hope I helped!" (Advisor 2, line 22)

This could be interpreted as indicating that the researcher did not provide sufficient feedback to the advisors on how their input had helped and contributed to the overall path of the research.

G. Other comments

Finally, it became apparent during the follow-up interviews that both advisors had enjoyed taking part in the research. This is illustrated by the following quote:

"Seriously, I really appreciate you having asked me ... I just hoped I ... err ... lived up to expectation and ... err ... have made some small contribution." (Advisor 2, lines 102-104)

The advisors were also looking forward to reading a summary of the research as a whole, and advising on how to take forward the findings, which clearly demonstrates a real interest in the research, as well as an understanding of their role in the research:

"Maybe ... then we ... err ... need another chat ... to ... err ... see how we ... can implement your recommendations ..." (Advisor 1, lines 82-83)

7.4.3 Researcher's reflective diary

A total of 42 entries were made in the researcher's reflective diary regarding the user involvement elements of this research. Interestingly, 35 of these were written in the first three years of the research, with 21 entries in 2003 alone, whereas only seven entries were made in the last two years of the research. This can be partly explained by the consultations with the local visual impairment support groups and identification of advisors to the research study all taking place at the start of the research. However, it is still of concern that contact with the advisors seemed to tail off towards the end of the research. Possible reasons for this include a lack of clear reasons for consulting and conflicting work priorities of the researcher. Ultimately both of these reasons became circular excuses, and it became difficult to break out of this train of thought. This point is illustrated by the following diary entry:

"I'm becoming concerned about the time that has lapsed since I last contacted my advisors. But what do I consult them about when there's nothing really to ask?" (11th May 2004)

In terms of the content of the entries, the majority related to specific consultations with the advisors to the research (these are described in more detail below). However, thoughts about the initial consultations at the local visual impairment support groups and the lead researcher's involvement with local societies for the blind and partially sighted, including giving informal talks, were also recorded. The researcher's observations at the time about the value of the local support group discussions were mixed, ranging from *"an extremely useful and encouraging discussion"* to *"I found it incredibly difficult to keep the group on the topic area"*. This is very interesting because now, four years on, reflecting back on these discussions, the researcher believes that the support groups were extremely helpful in shaping the overall research design.

The extent to which the advisors responded to each consultation varied considerably. Two advisors always responded either by email or with a telephone call. However, it was sometimes difficult to always get hold of the remaining advisors, which made the researcher question their commitment and interest in the research. The researcher also

queried her approach and whether the consultation needed to be more structured, particularly in terms of commenting on the research findings which, on the whole, were treated as 'for information' by the advisors, rather than open to challenge. A fairly unstructured approach was adopted in order to avoid "leading" the advisors to agree with a particular viewpoint. This approach might not be appropriate for everyone, however, and should be taken into account when designing future research. The following diary entry illustrates this point:

"I'm surprised that I haven't heard anything from them [the advisors] since. Maybe I wasn't clear enough in my instructions ... in what I wanted from them. But I don't want to be seen to be influencing their decision." (11th November 2003)

It was clear that at the start of the research, the researcher was very positive about the involvement of visually impaired advisors in the research, as illustrated by the following diary entry:

"The conversation emphasised the importance and value of my research." (7th February 2003)

However, over the next few months, the researcher started to question the approach:

"I'm beginning to wonder what I have let myself in for ... and how much time and resources will be needed." (30th March 2003)

"We had a useful catch up meeting, but unfortunately we actually spent very little time discussing my research." (23rd March 2003)

During the course of the research, the researcher became increasingly concerned as to whether the approach she was adopting was appropriate. As the period between consultations became longer, the researcher experienced feelings of anxiety and guilt, and feared that the involvement of advisors within the research was becoming "tokenist":

"I'm concerned that the user involvement aspects are being neglected." (11th April 2004)

"I'm starting to feel very guilty and, although I've always criticise people for just involving people for the sake of it, I think I now might be doing the same thing!" (23rd December 2004)

"I'm not sure how I can sustain their [the advisors'] involvement." (3rd March 2005)

"I'm feeling very anxious about the apparent lack of user involvement recently." (4th March 2007)

However, in response to these feelings, the researcher virtually always got in contact with the advisors shortly afterwards; for example:

"I'm pleased to be engaging with my advisors again, even if it's only a quick email updating them on my progress." (12th February 2005)

The researcher also found it difficult to know what to do when the advisors gave her conflicting advice or made suggestions that did not seem appropriate; for example:

"Although she seemed very excited about this idea, it really doesn't sound a great idea to me, from either a practical or academic viewpoint. The question is how do I explain that to her diplomatically?!" (12th August 2005)

One advisor was also very helpful in identifying and recruiting people with a visual impairment since birth or early childhood, thereby, alleviating the need to abandon this part of the research due to the initial low interest in the research amongst this group of people.

The following diary entry illustrates the researcher's relief at this:

"I am very grateful for his help in identifying participants. Without his intervention, the research would have been jeopardised. I suppose this demonstrates one of the real benefits of user involvement." (4th August 2003)

Finally, by keeping a reflective diary it was possible to note where changes were made to the overall design of the research both in response to the original discussions with the local visual impairment support groups and subsequent consultations with the advisors. The next section considers these changes in more detail.

7.4.4 Changes made to the research

Seven major changes were made to the research throughout its duration. Although it is not possible to say that these changes were made solely in response to the involvement of visually impaired people, the fact that they were highlighted within the researcher's reflective diary indicate that visually impaired people's comments directly influenced the research design.

As a result of attending the local visual impairment support groups, the researcher changed the terminology she used both in verbal and written correspondence, from 'visually impaired people' to 'people with a visual impairment'. This was out of respect and reflected the views expressed by those people present at the support group meetings. The phrase 'people with a visual impairment' put the person, rather than their impairment, first. Also in response to attending the support groups, the original research topic was expanded. Originally, the researcher was only interested in the health information needs of people with a visual impairment. However, discussions with visually impaired people revealed that they did not make the distinction themselves between health and social care, but instead saw it as a continuum. Young (2006) similarly reported that inter-organisational and related inter-professional divides are recognized as problematic from the user and carer perspective. Without visually impaired people's input into the research topic at this early stage, the researcher may have researched a very narrow topic which had little practical meaning to the people under investigation.

Finally, discussions at the local support groups resulted in changes being made to the methods used to collect data from visually impaired people. The researcher had originally planned to undertake focus groups with a mixed group of people with visual impairments. However, the people attending the support groups highlighted the wide range of visual impairments and recommended focusing on one or two groups of visually impaired people instead. As a result of this, the researcher elected to investigate in more detail the information needs of people with an age-related visual impairment and people with a visual impairment since birth or early childhood. In addition, those present at the support groups thought that people's information needs would be specific to an individual and to get a truly realistic picture it would be better to undertake individual interviews.

These findings support other research in the field which has found that involving service users at the research design stage can help to identify or develop approaches that suit a particular research context (Gray *et al.*, 2000). Interestingly, however, Smith *et al.* (2008) found that researchers reported difficulties with involving researchers at this early stage because they did not want to raise service users' expectations. Other researchers in the Smith *et al.* (2008) review had concerns about involving service users before ethical approval and/or research governance approval had been obtained. The involvement of

visually impaired people was a component of the original research proposal relating to this thesis, however, so this was not an issue here.

The involvement of the visually impaired advisors led to four main changes being made to the actual design of the research. Firstly, in response to their suggestions, minor changes were made to the wording of the topic guide used for the interview study. This mainly related to the ordering of the questions, in particular that the demographic and personal details about the participant were collected at the end of the interview rather than the start. It was thought that participants would be more willing to give this information later on when they felt more relaxed. Secondly, the researcher had originally anticipated using digital or CD recorders for the audio diary study. However, the advisors felt that most participants would feel more comfortable using equipment more familiar to them. Traditional tape recorders were, therefore, used instead. Thirdly, the advisors persuaded the researcher that a study exploring the role of local societies for the blind and partially sighted would be more interesting and beneficial than undertaking a quantitative study of people with AMD. Adopting this approach also enabled the information needs of visually impaired people to be viewed from a different perspective, that of an information provider. Finally, in response to comments made by the advisors, the emphasis of the questionnaire sent to managers of local societies was changed so that it focused on Internet use and barriers and facilitators to providing an integrated information service for people with a visual impairment. Without the advisors' input, these important areas may have been overlooked.

In addition, the visually impaired advisors commented on the findings of each of the individual studies which helped to verify and give some credibility (Lincoln and Guba, 1985) to the results. However, these comments did not result in any changes being made to the analysis and interpretation overall, although the advisors' interest in the identification of the local society as a major information source did result in this becoming the focus of a study in its own right. Smith *et al.* (2008) found that examples of the involvement of service users in the interpretation of research data were scarce in the literature, so the fact that the advisors were at least involved in this process here adds to this small body of knowledge. It would have been difficult for the advisors to have been more involved in the analysis and interpretation stages, however, because of the research being undertaken as

part of an academic qualification and the researcher needing to demonstrate that she had undertaken the work herself, *i.e.* that it was her own original work.

7.4.5 Changes made to practice

As well as changes being made to the research, the researcher was delighted to hear that as a result of her own involvement with a local society for the blind and the fact that one of her advisors worked there, the findings of the interview and audio diary studies were acted upon directly. In response to the finding about the lack of co-ordination of information about health and social care matters, the local society is now responsible for co-ordinating the eye information desk at the hospital, helping to ensure that people attending the ophthalmology department and low vision clinic have easy access to verbal and written information on a wide range of eye conditions, as well as the services available to support them. It is highly unlikely that the research findings would have been used in this way without the direct involvement of visually impaired people in the research process.

7.5 Discussion of Findings

7.5.1 Summary of key findings

Consultation with several people with visual impairments at the start of the research certainly helped to clarify the terminology used, as well as the scope, questions and methods used for this research. A longer term relationship with five visually impaired advisors contributed further to the design of the research (see Section 7.5.2). The interviews with the advisors resulted in a framework (Figure 8) that can potentially be applied to other user involvement studies. Regardless of the user group, the users will have their own personal experience of a particular issue that will ultimately affect their reasons for getting involved in a research study, their actual role in and contribution to the research, the benefits they gain from being involved, and in their suggestions for improving research in the future. Interestingly since conducting this research, Oliver *et al.* (2008) have published their own framework for describing user involvement in research. However, this focuses on the degree of public engagement, ranging from 1 ('lay control' to 4 ('minimal'), and the researchers' degree of engagement, ranging from 1 ('inviting lay groups') to 4 ('minor partner or absent'), rather than the whole process of public involvement.

Finally, by keeping a diary, the researcher has been able to capture her thoughts and experiences of involving visually impaired people throughout the course of the research. Interestingly similar themes seemed to emerge between the interviews with the advisors and the researcher's diary. For example, both the advisor and researcher commented on the need for more regular contact, even if this was for simple updating purposes. The rest of this section goes on to consider some of the more overarching findings in more detail.

7.5.2 *Impact of user involvement on research design and outcomes*

In Section 7.4.4, seven areas of the research were identified where changes were made in direct response to feedback from visually impaired people. Six of these areas related specifically to the scope of the research and the research design and methods; for example, the inclusion of social care information, as well as health care information and the adoption of individual face-to-face interviews in preference to focus groups. It is not possible to be certain that these changes would not have been made anyway as a result of discussions with other people. However, the comments made by the visually impaired people taking part in the consultation exercises definitely influenced the course of the research and its outcomes, as well as prevented obvious mistakes being made. From the researcher's (and probably the users') perspective, these changes resulted in the research being more practical and accepted by participants to the individual studies. Indeed, without user involvement and the evidence emerging from this research, improvements would not have been made to the provision of information at a hospital ophthalmology department, as described in Section 7.4.5.

7.5.4 *Users are still Individuals*

Perhaps one of the most unexpected findings from both the consultation and collaboration exercises, certainly from the researcher's point of view, was being reminded of the advisors' own personal difficulties associated with having a visual impairment. By engaging people in research as advisors, there is a real danger of forgetting that they are themselves individuals who are at various stages of coming to terms with their impairment and who still encounter their own unique difficulties which may or may not be related to their visual impairment. This may sound obvious, but it is a very important point which should not be overlooked.

7.5.5 The mutually beneficial relationship

Originally, it was envisaged that the advisors' role in this research would mainly be at the level of 'consultation', as defined in Hanley *et al.* (2004) and described in Section 3.9.4. The Oxford English Dictionary defines 'consultation' as an, '*act or process of consulting*'. However, it is now clear that the advisors' involvement in this research study was substantially more than this, perhaps because of the long duration of the study. Although it would be inappropriate to label their involvement as 'user led, it does go beyond traditional 'consultation' and certainly includes elements of 'collaboration' (Hanley *et al.*, 2004). This evolving role of visually impaired people in the research process is in line with Smith *et al.*'s (2008) finding that very few published studies, at least within the field of nursing, midwifery and health visiting, have a clear rationale or objectives for involving service users. Although the researcher was clear that she wanted to involve visually impaired people in this research, this was mainly due to the fact that she thought that this was the right thing to do (Boote *et al.*, 2002), rather than there being any clear evidence that public involvement in research is effective.

The findings from the interviews with the advisors and the researcher's reflective diary have emphasised that the importance of the relationship between the advisor and researcher, an issue which was also recently highlighted in Smith *et al.*'s (2008) review. Ideally, this relationship should be mutually beneficial, *i.e.*, not only do the advisors contribute to the research in terms of their contacts, direct experience of having a visual impairment and/ or prior research experience, but, by being involved, they should receive something in return, be that ownership of the findings, research experience, or simply being able to share their experiences with someone. In this respect it was interesting to find that, prior to the initial interviews, the advisors had not really given the latter much consideration; they originally agreed to take part without explicitly expecting anything in return.

7.5.6 Methodological issues

It is helpful to highlight some of the methodological issues emerging from the public involvement aspects of this research. Firstly, although all three local visual impairment support groups appeared to be interested and willing to take part, only one group seemed to really understand the purpose of the discussion and the aims and possible outcomes of

the proposed research. This illustrates both the difficulties of explaining user involvement to the public, but also the need for an experienced person to facilitate such groups. Secondly, as a result of having spoken to the advisors on several occasions prior to the initial and follow-up interviews, it was difficult to establish a traditional 'interviewer-interviewee' relationship. For instance, the advisors had a tendency to ask the lead researcher questions throughout the interview ('role-reversal') and to offer advice about the study (*e.g.*, in terms of research implementation). This is not necessarily a criticism of the approach, but perhaps reflects the 'public involvement' ethos of the research and the advisors' inherent desire to inquire and offer advice. The experience certainly highlighted considerable differences between conducting interviews with 'users' as opposed to 'subjects' of research.

7.5.7 More effective involvement of visually impaired people in research

The follow-up interviews with the advisors and the researcher's reflective diary have yielded some useful suggestions about the involvement of visually impaired people in future research studies. In terms of the frequency of consultation it is important to strike a balance between being regular enough to maintain interest and being too frequent to be onerous. For this research, contact was made approximately every three to four months. It emerged that this was probably not frequent enough and it would have been helpful for updates to be sent monthly. In terms of the method of contact, although the advisors were happy to consult by email and by telephone, it was clear that on occasions (*e.g.*, at key stages in the research), face-to-face meetings, perhaps consisting of all the advisors, would have been more appropriate.

Despite the usefulness of the job description, further clarification of the role of the advisor in the research process and feedback on their suggestions was clearly required. This is illustrated by the fact that one advisor did not feel able to influence the course of the research, whilst the researcher separately expressed concern about how to explain to an advisor that, although their suggestion was interesting, it was not appropriate to take forward. In future studies it will also be important to consult users more on the actual findings of the research. As noted previously, this was done more for information and verification purposes for this study.

Finally, the advisors to this research evidently wanted to be more involved in this research, particularly in undertaking some of this research. Although this will not always be possible, it is recommended that users are consulted at the start of the research about the extent to which they want to get involved in the research. While some people may only be interested to advise, others may want to conduct interviews, *etc.*

It will be interesting to see whether new national initiatives, such as the development of Local Involvement Networks (LINKs) (House of Commons Health Committee, 2007) will facilitate the more effective involvement of the public in research, or whether the emphasis will solely be on the NHS and local authorities consulting about service developments.

7.5.8 Research limitations

Inevitably there were limitations associated with the way in which visually impaired people were involved in this research, as well as the methods used to evaluate their involvement. Firstly, for both the consultation and collaboration, a convenience sample of people with a visual impairment was sought. All the people contributing to the research were registered as being either sight impaired or severely sighted impaired and were already aware of, and in contact with, most of the relevant health and social care organisations. However, as noted in the literature review (Chapter 2), it is well-documented that official registers underestimate the number of people with a visual impairment by a factor of three (Bruce *et al.*, 1991, European Blind Union, 2002a) and, therefore, are not in contact with such services. The issue of “tokenism” and “representativeness” in relation to user involvement has been raised by various authors (*e.g.*, Beresford, 2007). However, there is now a consensus that it is better to involve some people in the research process, rather than avoid the issue because of fears of not being able to involve people from marginalized groups (Beresford, 2007).

The original identification of the advisors was potentially prone to bias. The pre-determined person specification in the job description helped to ensure that the advisors involved in these interviews were selected in an objective manner. Although it has been argued (*e.g.*, by Lincoln and Guba, 1985) that it is inappropriate to generalise qualitative findings, attempts should still be made to ensure that the findings are potentially transferable to other individuals or groups in similar situations. The advisors did reflect the

population under investigation in this thesis and, on the whole, the advisors selected for evaluating the 'public involvement' aspects of the research provided a good representation of different viewpoints.

In terms of the methods, the discussions at the local visual impairment support groups were not tape recorded and transcribed, as this was not deemed appropriate as described in Section 7.3.1. It is, therefore, possible that the researcher may have selectively reported and interpreted the discussions. The researcher did make notes throughout and immediately after the discussions, however, and a summary of the findings was sent to the group organisers for their comments in an attempt to reduce the chances of such bias being introduced.

Despite these potential limitations, this study has successfully evaluated the role and impact of visually impaired people's active involvement in this research, a feat which has rarely been achieved in the past, as highlighted in Section 3.9.

7.6 Conclusions and Implications

To conclude, involving visually impaired people in the design of this research has proved to be a very useful and interesting experience, both from the researcher's and the advisors' point of view. By involving visually impaired people, the researcher was able to gain a greater insight into the issues facing people with a visual impairment, not only in terms of health and social care information, but also concerning more general day-to-day issues. Despite the added stresses and time implications, the researcher would strongly recommend this approach to others, particularly to other Ph.D. students.

Based on these findings it is possible to make a number of recommendations for future research in this field. Firstly, researchers embarking on a new study should consider whether it would be appropriate to involve one or more visually impaired people and, if so, to what extent. If visually impaired people are to be involved it is important to ensure that the frequency and method of contact meets the needs of those being involved and this should be agreed at the start of the project and subsequently reviewed throughout. Finally, where possible, visually impaired people should be encouraged to take a more active role in the research, such as undertaking interviews themselves.

Given the paucity of evidence evaluating public involvement in research, as noted by various authors (*e.g.*, Boote *et al.*, 2002; Nilsen *et al.*, 2006; SCIE, 2007d) and highlighted in Section 3.9, this small-scale evaluation of the involvement of visually impaired people in this research has contributed to our understanding of the benefits of public involvement in research and has demonstrated that such evaluations do not require major additional resources, just time and commitment from the researcher and users.

CHAPTER 8. DISCUSSION

8.1 Introduction

The previous four chapters have presented the findings of the major studies of this research: an interview study with two groups of visually impaired people (people with an age-related visual impairment and people with a visual impairment since birth or early childhood); an audio diary study with a small sample of older visually impaired people; a national survey of managers of local societies for the blind and partially sighted; and an evaluation of the active involvement of visually impaired people in the design of this research. This chapter brings together the findings across these different studies, discusses how they relate to the existing literature (presented in Chapters 2 and 3) and how they answer the original research questions, as well as highlights how this research contributes to new knowledge in the field.

8.2 Triangulation of Findings

In order to obtain multiple perspectives (Nolan and Behi, 1995) on the health and social care information needs and behaviour of people with a visual impairment, the findings from the different studies have been triangulated, as discussed in Section 3.6. By triangulating the findings, breadth and depth has been added to the analysis, and a more holistic understanding (Jones and Bugge, 2006) of the field has been achieved. The rest of this section, therefore, considers the knowledge gained through using these different methods, whilst Section 8.3 relates the findings to theory, in particular to two established information models.

8.2.1 Methodological triangulation

As noted above, this research has used three different methods: semi-structured interviews, audio diaries and a quantitative survey. Each approach individually has contributed to our understanding of the health and social care information needs and behaviour of visually impaired people, but together the different methods have created a more complete and certain picture. For example, the findings of the audio diary study

confirmed the results that emerged from the interview study. The fact that the same framework could be used to analyse both the interview and audio diary studies supports this. However, as discussed in Chapter 5, there were some noticeable differences; for example, none of the audio diary participants explicitly referred to information about eye conditions or information about employment, education and training. Possible reasons for this were suggested in Section 5.4.6, and related to the characteristics of the participants, namely that the audio diary participants were older and no longer working and had had a visual impairment for several years and, therefore, their actual information needs were different.

The format of information was a key theme in both the interview study and audio diary study. However, the frequency of reference to difficulties reading correspondence in the audio diaries indicated this was a frequent problem, rather than simply one of many difficulties. The timing of information appeared to be a more important issue for the interview study participants, perhaps because the diagnosis process had taken place more recently for some participants, particularly those with AMD. Although the quantity and quality of information were key themes in the interview study, little reference was made to these issues in the audio diaries. This may be because the researcher was able to prompt the participants for this information in the interview study, but not in the audio diary study. The interviews explicitly asked participants about the way in which they accessed information, *i.e.*, whether they received, acquired and/or sought the information. It was harder to extract this type of information from the audio diaries.

Although various information sources were referred to by both the interviewees and diarists, it was evident that the sources differed between the two groups. This suggests that participants' use of different information sources varied over time. Alternatively, it may be possible that participants did not accurately recall their use of information sources in a one-off interview situation which took place several months or even years after the event. This finding only emerged as a result of the audio diary study; that is, if only an interview study had been undertaken, the relative importance of societies, organisations and support groups may have been understated and may not have resulted in the survey of managers of local societies. For the interview study participants, the major source appeared to be health care professionals, whereas for the audio diary participants the major information sources were societies, organisations and support groups, and friends and family. Section

5.4.6 started to provide some possible explanations for this difference; for example, the diarists tended to 'acquire' most of their information, perhaps because they were in less direct contact with health and social care professionals due to the time elapsed since the time of their diagnosis. Interestingly, no mention was made to the Internet or NHS Direct as a source of information by the audio diarists. It is not clear whether these information sources were not used at all, were not used during the data collection period, or whether the participants simply did not record anything about using these sources. In contrast, the interview participants were explicitly asked about their use of the Internet and NHS Direct as information sources for health and social care information.

Both the interview study and audio diary study suggested that various factors may have affected the information behaviour of the visually impaired participants. These included health factors, such as the presence of other health conditions and/or disabilities and the type, length and registration of visual impairment; personal factors, such as a person's degree of independence and their acceptance of their visual impairment; social support factors, such as the availability of support from friends and family; as well as information factors, such as their understanding of the word 'information' and participants' interactions with information sources. In some cases these factors were explicit from the interview and diary transcripts, whereas other factors were more indirect, particularly in relation to participants' understanding of the word 'information'. It was interesting to find that these factors were more evident in the audio diaries than in the interviews, and, thereby, helped to give a greater insight into the lives of older visually impaired people, particularly the psychological aspects of having a visual impairment and, more generally, getting older.

Participants in both the interview and audio diary studies identified specific improvements that could be made in the provision of health and social care information. These suggestions were explicit in the interview study because participants were asked to put forward ideas, whereas the suggestions were more implicit in the audio diaries and emerged from difficulties participants faced on a day-to-day basis. Overall, the suggestions were similar across the two studies, however, and focused on the need to improve the co-ordination and targeting of information, and the need to provide more information in alternative formats as a matter of course.

Within-methods triangulation (Ritchie and Lewis, 2003) was used within Chapter 6 to analyse the findings from the local society managers' questionnaire alongside the follow-up interviews with a sample of local society managers. The follow-up interviews, for example, helped to reinforce the findings from the questionnaire, but also provided a wider perspective. In terms of reinforcing findings from the questionnaire, the follow-up interviews identified the Internet as a major and increasing source of information to both visually impaired people and those people supporting them. In addition, the follow-up interviews reinforced the barriers and facilitators to providing an integrated information service for visually impaired people which were identified as part of the questionnaire. In terms of providing a wider perspective ("triangulation for completeness"), the follow-up interviews enabled local society managers to explain that their main role was to "signpost" clients to relevant information and sources of support, whereas the questionnaire simply identified the main topics local societies provided information about to visually impaired people. It also became clear from the follow-up interviews that local societies tended to use existing information and leaflets on eye conditions rather than create their own information. The reasons and nature of Internet use by local societies could be explored in more detail in the follow-up interviews and, thereby, helped to provide a more complete picture. Finally, the follow-up interviews enabled participants to give and discuss explicit examples of integrated working which will ultimately hopefully help to inform future practice.

Finally, the quantitative survey has enabled the information needs and behaviour of visually impaired people to be considered from a different viewpoint, that of managers of local societies for the blind and partially sighted. It has helped to identify gaps and overlaps in current information provision by local societies. For example, it is clear that some visually impaired people are asking local societies for information about specific eye conditions, rather than requesting this from health care professionals. The survey of local society managers, like the interview study, identified the Internet as a key source of information on health and social care matters for visually impaired, but also highlighted some of its drawbacks which need to be addressed.

Having reflected above on the added value of using a variety of methods in this research, the next section triangulates the findings within the context of existing theory, in particular two established information models.

8.3 Theory Triangulation: Analysis in the Context of Two Information Models

Information models, as discussed in Section 2.4.3, provide a framework (Attfield *et al.*, 2006) for analysing and triangulating the results of the interview and audio diary studies, as well as for allowing the health and social care information behaviour of visually impaired people to be explored in more depth. This section analyses the findings within the context of two specific information models: Moore's (2002) model of social information need and Wilson's (1999) revised model of information behaviour. Moore's model was chosen because it was specifically developed in relation to the information needs of visually impaired people, whereas Wilson's model is a generic model of information behaviour which has the potential to be applied to the information behaviour of people with visual impairments. This analysis is published in Beverley *et al.* (2007).

8.3.1 Moore's (2002) model of social information need

Moore (2002) described social information as having six different dimensions: function, form, clusters, agents, users and mechanisms. Each of these are analysed within the context of the interview and audio diary studies below.

8.3.1.1 Function

Visually impaired people, particularly within the interview study, reported needing information for a variety of different purposes. For example, participants needed sufficient information at critical decision-making points, such as deciding whether or not to proceed with a treatment. This is illustrated by the following quote, cited in Chapter 4, by a person with an age-related visual impairment who was contemplating undergoing laser treatment:

"... and then told me exactly the pros and cons of laser treatment ... that it has a 50% chance of succeeding and a 50% chance of it not returning. So a 25% chance of it working overall." (A17, lines 157-159)

This corresponds with Moore's (2002) suggestion that people need social information to support them as citizens and as consumers, *i.e.*, people with a visual impairment need to be adequately informed about the range of different treatment options to which they are entitled and that are available to them ('information for citizenship'), as well as the advantages and disadvantages of each of them ('information for consumption').

8.3.1.2 Form

From both the interview study and audio diary study, it was clear that participants sought, processed and absorbed many different kinds of information, referred to as 'environmental scanning' by Moore (2002). Moore (2002) acknowledged that information alone was not always enough to trigger action. This was supported by these studies in that some participants reported feeling overwhelmed with the amount of information provided at the time of diagnosis, as well as the various factors (similar to Moore's 'attitudinal barriers') which either inhibited or encouraged people from accessing health and social care information. The following quotes, one from an interviewee, cited in Chapter 4, and one from a diarist, cited in Chapter 5, aptly illustrate this point:

"No, I'm not bothered. What I don't know can't ... harm me. I suppose ... in some ways I'd rather not know." (A11, line 71-72)

"... the more clutter ... the more confused I get ..." (Audio diarist 6, lines 223-224)

Other authors have found a similar pattern; for example, Miller (1987) discovered that some people did not want information about their health condition, but instead chose to avoid, or even 'blunt', such information.

From the interview study it also emerged that participants identified a series of questions relating to their visual impairment which they subsequently asked during their medical consultations (similar to Moore's 'answers to questions'). For example:

"... you've got to go ... armed with questions ... and ask for what you want to know." (B12, lines 232-233)

This determined approach to obtaining information may be particularly important to visually impaired people where an appointment with a health care professional may be seen as the ideal opportunity to obtain information that is not so readily available at other times and routes, such as books and magazines.

8.3.1.3 Clusters

Moore (2002) described two different approaches to considering information needs: 'hierarchies of need' and 'life events'. He identified eight main clusters of need (the

condition, its treatment and likely outcome; benefits and money; general health; aids and equipment; housing and accommodation; mobility; services and facilities; and employment, education and training) (Moore, 2000), but he was unable to identify the actual hierarchy of information needs that were experienced by visually impaired people. The findings from the interview study and audio diary study progress this further by refining these cluster names and proposing a hierarchy of information needs for visually impaired people taking part in this research.

The clusters identified in the interview study, in order of importance to the participants, were, therefore:

1. The eye condition, in particular information about the diagnosis, prognosis, treatment options, and its causes.
2. Health and social care services and facilities, including reading general correspondence and assistance with filling forms in.
3. Aids, adaptations and equipment, such as low vision aids; talking books; talking watches; liquid level indicators, *etc.*
4. General health care, including techniques for administering medications, such as eye drops and tablets; reading medical information, such as appointment letters, prescriptions, medicine labels, hospital notices and signs, *etc.*
5. Benefits and money, including knowing about the financial benefits available to visually impaired people; recognising different coins and note; and using cash machines.
6. Mobility, including using public transport, shopping, eating out, going on holiday, *etc.*
7. Housing and accommodation, including performing household chores, such as cooking and cleaning.
8. Employment, education and training.

However, the hierarchy amongst the audio diary participants was slightly different and only consisted of six clusters:

1. Health and social care services and facilities, including reading general correspondence and assistance with filling forms in.
2. Aids, adaptations and equipment, such as low vision aids; talking books; talking watches; liquid level indicators, *etc.*

3. General health care, including techniques for administering medications, such as eye drops and tablets; reading medical information, such as appointment letters, prescriptions, medicine labels, hospital notices and signs, *etc.*
4. Benefits and money, including knowing about the financial benefits available to visually impaired people; recognising different coins and note; and using cash machines.
5. Mobility, including using public transport, shopping, eating out, going on holiday, *etc.*
6. Housing and accommodation, including performing household chores, such as cooking and cleaning.

As noted previously (Section 8.2), the findings from the interview and audio diary studies have complemented each other, so, for example, the two studies together have given a more complete picture of the hierarchy of information needs, whilst the audio diary study findings have reinforced the findings of the interview study. The differences between the hierarchies identified between the two studies may be explained in part by the characteristics of the audio diary participants, *i.e.*, all the participants were aged 60 years or older and had had a visual impairment for several years, whereas the interview study participants were from one of two groups: people with an age-related visual impairment and people with a visual impairment since birth or early childhood, and they generally had had a more recent diagnosis. The audio diary participants were, therefore, less interested in accessing information about their eye condition, either because they had already obtained the necessary information, or because they no longer wanted to know any more about their condition. Similarly, information about employment, education and training opportunities was of less importance to the older visually impaired people in both studies.

The extent to which these information needs were met and the route which they were received, acquired and/or sought varied for the individuals taking part in both studies. It was also clear that participants had various unmet information needs. These met and unmet needs are described in more detail in Chapters 4 and 5. However, it is noteworthy that the majority of information from the higher clusters of the hierarchy were received, acquired or sought, whereas most of the information from the lower clusters of hierarchy, particularly for the audio diary participants, was acquired through societies, organisations and support groups, and friends and family. This may be because these lower clusters were seen as a lower priority by the major information providers and because not all participants had information needs relating to them.

8.3.1.4 Agents

Moore's (2002) model focused on three different initiators of the information activity: information 'seekers', information 'providers' and information 'processors'. In the interview and audio diary studies not only were information 'seekers' (*i.e.*, visually impaired people) and information 'providers' (*i.e.*, health care professionals, social care professionals, *etc.*) identified, but it was also evident that organisations, such as the local society for the blind, were acting as information 'processors', *i.e.*, processing and digesting information on behalf of users. This latter issue led to the survey of managers of local societies for the blind and partially sighted being undertaken, as described in Chapter 6. The findings from this survey reinforced the role of local societies as 'processors' of information.

In line with Moore's 'trust and authority' theme, described in Section 2.4.7, several participants expressed concern about the quality of the information they had received, sought or acquired. For example, the following interviewee, cited in Chapter 4, expressed reservations about information obtained from the Internet:

"I'm overly cautious of what people put out there. And ... I know it's got some wonderful facilities on there ... but I know it's also full of ... lots of ... err ... nonsense." (B10, lines 184-187)

While caution about the quality of information available on the Internet is widespread, and a particular concern in relation to health and social care information (Silberg *et al.*, 1997; Eysenbach *et al.* 1998), it is possible that people who have been blind since birth, such as the above participant, have additional concerns, because they are less able to visualise and evaluate this source of information, and are, therefore, more willing to trust more traditional sources.

8.3.1.5 Users

The interview study in particular identified some similarities and differences between the information needs of two groups of visually impaired people, namely people with an age-related visual impairment and people with a visual impairment since birth or early childhood. In doing so, it has also added support to the notion that visually impaired people cannot be regarded as a single homogeneous group. This is illustrated by the following quote from an interviewee, cited in Chapter 4:

“Well, that’s a difficult one isn’t it ... because ... you see ... everybody’s different ... and we all need it in different ways ...” (A12, lines 967-968)

Moore (2000) specifically identified eight different groups of people that could be thought of as having a common core of information needs according to: the degree of their visual impairment, whether they were recently visually impaired people, older people, children, people with multiple disabilities, people with ethnic minorities, carers, and professionals. This research included participants who were from several of these groups, *i.e.*, the participants with AMD were, by definition, older people, and included participants who had been diagnosed in the last 12 months and had co-morbidities. However, the study did not include professionals, or explicitly consider the information needs of carers, although three visually impaired couples were interviewed.

It is important to note, however, that individual differences and preferences still prevailed within each of the two groups of visually impaired people, with the factors affecting information behaviours, identified in Chapter 4, playing a key role. Both the interview study and audio diary study identified several factors that may affect a visually impaired person’s information behaviour. These related to the presence of other health conditions and/or disabilities; type, length and registration of visual impairment; degree of independence; support from family and friends; personal acceptance of visual impairment; willingness and ability to pay for aids, adaptations and equipment; the “expert patient”; participants’ understanding of the word ‘information’; and participants interactions with information sources. For example, most participants in this research experienced one or more co-morbidities, *i.e.*, other health conditions or disabilities, such as arthritis and hearing impairments, which further hindered their lifestyle. Visually impaired people with co-morbid conditions are, therefore, at a particular disadvantage, in that their visual impairment acts as a barrier to information about their visual impairment and the associated condition.

8.3.1.6 Mechanisms

A range of different mechanisms can be used to meet people’s information needs. Moore (2000) considered these in terms of ‘recording and storage’, ‘transmission and communication’, and ‘tailoring and customisation’. Although this research has not considered mechanisms in this manner, it has highlighted the importance of providing

information in a participants' preferred format, such as on audio tape, on CD ROM, via email and/or on the Internet. This is illustrated by the following quote from an interviewee, cited in Chapter 4:

"... I think ... a wider range of formats should be available ... i.e., large print, audio cassette ... Internet ... mind you, you can't really send letters on Internet ... but ... maybe emails ... floppy disks ... erm ... Braille ... err ... just a wider range so that people have got more choice ... erm ... instead of having a standard print letter that nobody can read." (B2, lines 151-155)

8.3.2 Wilson's (1999) revised model of information behaviour

Unlike Moore's (2002) model, Wilson's models were not specifically developed with the information needs of visually impaired people in mind. Testing the results from this research with Wilson's model will, therefore, provide an additional test of the robustness of the findings, as well as establish whether the model can be applied to the information behaviour of visually impaired people accessing health and social care information.

The revised Wilson (1999) model, described in Section 2.4.6, consists of five main components of information behaviour: the context of information need, activating mechanisms, intervening variables, information seeking behaviour, and information processing and use. Each of these components in relation to the findings of the interview and audio diary studies is discussed in more detail below.

8.3.2.1 The context of information need

Wilson's models were based on two main propositions: first, that information need is not a primary need, but a secondary need that arises out of needs of a more basic kind, and, second, that in the effort to discover information to satisfy a need, the enquirer is likely to meet with barriers of different kinds (Wilson, 1981). Both of these propositions are reinforced by the findings of both the interview study and audio diary study. For example, many participants did not explicitly state their information needs, but instead described areas of need and/or difficulties they faced in various aspects of their life (*e.g.*, taking tablets, cooking, eating out, filling forms in, *etc.*) from which it was possible to infer an information need. The following example from an interviewee with an age-related visual impairment, cited in Chapter 4, illustrates this point:

"You mean, tablets like? I've had no end of problems with them. I don't know what I'm taking. I'm on so many, you see ... When you're on so many different drugs ... it's easy to get confused." (A11, lines 80-83)

Although this person did not explicitly state that he needed information in relation to taking medications, his description of the problems he faced in taking them indicated that information on each medication, and a means of differentiating between the different medication, was required. Therefore, in accordance with Wilson's model, his primary need was to take medication, but a secondary need for information arose from this. The person's visual impairment presented a barrier to him gaining that information.

8.3.2.2 Activating mechanisms

Wilson's (1999) model embodied a set of questions about information behaviour, in particular, why some people need prompt information seeking more so than others ('stress/ coping theory'); why some sources of information are used more than others ('risk/ reward theory'); and why people may, or may not, pursue a goal successfully, based on their perceptions of their own efficacy ('social learning theory'). An example of 'stress/ coping theory' from this research is the different coping strategies exhibited by participants (e.g., some interviewees chose to ask their ophthalmologist more information about their visual impairment whereas other participants 'blocked' any further information).

Participants in the interview study expressed a preference for health care professionals and the local society for the blind as an information source; this may be because the benefits (or 'rewards') of doing so were greater than the 'risks'. Finally, it was clear from both the interview study and audio diary study that 'social learning theory' was involved; for example, participants acquired information and knowledge through less formal contacts, such as via local support groups and family and friends.

8.3.2.3 Intervening variables

Wilson (1999) identified five major types of 'intervening variables' which could potentially affect a person's information behaviour. These were: psychological, demographic, role-related or interpersonal, environmental and source characteristics. This research has also identified a series of factors which may have acted as a barrier, or facilitator, to the

information behaviour of visually impaired people. Although the labels used here are slightly different, they are in accordance with Wilson's 'intervening variables'. For example, the demographic background (such as age, gender, ethnic origin), the individual's social role (such as degree of independence, support available from friends and family, involvement with local support groups, etc.), the individual's psychological status (e.g., acceptance of having a visual impairment), environmental variables (e.g., registration status, access to the Internet, willingness and ability to pay for aids, adaptations and equipment), and the characteristics of the sources (e.g., availability of information in alternative formats, reliability of the information provided, interactions with different information providers as discussed earlier) may all have affected participants' information behaviour.

A particularly interesting finding from this research, however, is that, in addition to Wilson's list of 'intervening variables', there are further issues that must be taken into account when considering the information behaviour of visually impaired people accessing health and social care information. For example, in both the interview study and audio diary study, variables relating to the person's visual impairment (e.g., type, degree and length of impairment) and the presence of other health conditions and disabilities were also identified, all of which may affect an individual's information behaviour.

8.3.2.4 Information seeking behaviour

Different types of search behaviours were advocated by Wilson (1999): passive attention, passive search, active search and ongoing search. The findings from this research, particularly the interview study, are in accordance with this. As discussed in Chapter 4 under Theme A.6 Access route, in addition to receiving information from a variety of sources ('passive attention'), participants 'acquired' information ('passive search'), as well as actively sought information in order to meet their health and social care information needs. Examples of 'passive attention' included the information received from health and social care professionals relating to participants' eye conditions, health and social care services and facilities, and aids, adaptations and equipment. Participants also passively sought information from family, friends, local support groups and the mass media.

8.3.2.5 Information processing and use

In accordance with Wilson's (1999) model, it was evident from the research that if participants' information needs were to be satisfied then 'information processing and use' was an essential part of the feedback loop, *i.e.*, participants, having received, acquired or sought the necessary information then had to make sense of this information. This was illustrated by the quote presented above from the participant (A17), cited under Section 8.3.1.1, who had to weigh up the advantages and disadvantages of receiving laser treatment for AMD.

8.3.3 Summary and discussion

Moore's (2002) model of social information need and Wilson's (1999) model of information behaviour have both been useful in analysing and interpreting the findings from both the interview and audio diary studies. The results from this primary research have supported the six dimensions of social information need for people with a visual impairment identified by Moore (2000, 2002) in his review of previous studies. However, it has also been possible to build on Moore's clusters of information needs (Moore, 2000), by developing these into an ordered hierarchy of importance from the perspective of the visually impaired participants in this research. Moore's model was fairly descriptive, however, based solely on a review of the literature and simply listing information needs. It also did not account for all of Wilson's (1999) 'intervening variables' which appear to be important in determining information behaviour among people with a visual impairment.

This research has also demonstrated that Wilson's (1999) model of information behavior, developed with more general information situations in mind, can be applied, although modified slightly, to a specific group of people. In particular, this research has identified an additional 'intervening variable' category relating to an individual's health characteristics, in this case the type, degree and length of visual impairment and presence of other health conditions and disabilities. There is, therefore, potential for a modified version of Wilson's (1999) model to contribute to our understanding of information needs in the context of other groups, diseases and conditions.

8.4 Summary and Discussion of Key Findings

The research reported in this thesis has generated a wealth of data which considerably expands our knowledge and understanding of the health and social care information needs and behaviour of people with visual impairments. This section attempts to summarise and discuss the key overarching findings under four broad headings. The first two headings relate to the actual health and social care information needs and behaviour of visually impaired people and the extent to which these needs are currently being met, particularly by local societies for the blind and partially sighted. In contrast, the second two headings focus on the two major novel aspects of this research, that is, the use of audio diaries as a research method, and the involvement of visually impaired people in the research process.

8.4.1 The health and social care information needs and behaviour of people with a visual impairment

All components of this research have contributed to our increased knowledge and understanding of the health and social care information needs and behaviour of people with a visual impairment, but particularly two groups of visually impaired people: people with an age-related visual impairment and people with a visual impairment since birth or early childhood. On the whole, the information needs of participants in this research mirrored the eight 'clusters' identified by Moore (2000) and have extended the findings of Beverley *et al.*'s (2004) systematic review concerning the three major types of health information ('information about visual impairment and coping with visual impairment', 'information for healthy living', and 'information about accessing health services'), by explicitly identifying aspects of health and social care that visually impaired people need information about. In addition to requiring specific information about their eye condition, such as the diagnosis, prognosis, treatment options, and its causes, visually impaired people are also likely to need information about different health and social care service and facilities; aids, adaptations and equipment; general health care, such as administering medications and reading medical information; benefits and money; mobility issues; housing and accommodation; and employment, education and training opportunities.

Chapter 2 indicated that information needs generally arise out of a desire to meet one or more of the three basic human needs: physiological, psychological and cognitive (Nicholas, 2000). The findings from the interview and audio diary study support this. For

example, the visually impaired participants in this research clearly had physiological needs relating to their health and well-being; psychological needs relating to them coming to terms with their visual impairment; and cognitive needs relating to them learning how to adjust to having a visual impairment. It was also evident, as noted by Nicholas (2000), that the participants in this research did not always state what their information needs were explicitly, but instead the researcher had to extract these needs from the comments they made.

Although there are similarities with the information needs of people with other health conditions and disabilities (*e.g.*, Beaver and Booth, 2007), the visually impaired people taking part in this research were generally less concerned with the likelihood of cure and spread of disease, but were more interested in treatment options and the sources of help and support available. This is probably because visual impairments are rarely life threatening, as is the case of cancers, for example.

In line with other literature in the field (*e.g.*, Beverley *et al.*, 2004), one of the key themes emerging from this research was the format of information and the fact that information was not always provided in an accessible way. In addition, much of the information provided is only verbal, yet it is recognised that this needs to be supplemented with written or taped information to reinforce messages (Raynor and Knapp, 2000). This issue has already started to be addressed; for example, since undertaking this research, the RNIB and Datapharm have launched an Internet and telephone service to provide Patient Information Leaflets (PILs) in accessible formats to people with sight problems (Datapharm, 2007). In addition, as described in Section 2.5, the Department of Health is starting to roll out "information prescriptions" across the health and social care sectors (Department of Health, 2006b). Information prescriptions aim to impact positively on service users, carers and professionals, by developing an integrated and seamless system for providing information to users and carers that help them better manage their own care (Office for Public Management, 2008).

The findings here also support Beverley *et al.*'s (2004) and Attfield's *et al.* (2006) suggestion that other aspects of information, such as the timing, quality, quantity and support mechanisms are also important in ensuring that visually impaired people have access to accurate, up to date and timely information. Patients' information needs will

inevitably change and evolve in response to changing situations, for example, as a person moves through the disease process (Attfield *et al.*, 2006). For example, it was evident, particularly from the interview study, that most of the information that participants received was verbal at the time of diagnosis. For most people, this was inappropriate and insufficient, and individuals had to supplement this with additional information which they either sought or acquired from other sources. It was, therefore, encouraging to find that there had been a noticeable improvement in recent years in the provision of information at the local hospital, as illustrated by reference to the “*yellow book*” (A4, line 87).

Both the interview study and audio diary study highlighted the many different sources people with visually impairments have to consult in order to obtain the information that they require. Whilst some people, particularly those with an age-related visual impairment, were mainly dependent on health care professionals, other people relied on societies, organisations and support groups, as well as friends and family to provide them with the information they required. Interestingly, the local society for the blind and partially sighted emerged from the interview study and audio diary study as one of the major information providers and this resulted in this issue forming the basis of a separate study (Chapter 6).

Despite having clear potential to improve access to health and social care information to visually impaired people, the findings of this research suggest that newer sources of information, such as NHS Direct and the Internet, are generally underutilised by visually impaired people, as well as by local societies for the blind and partially sighted. The various barriers to access (*e.g.*, cost of specialist accessibility software) identified here and by others (*e.g.*, Williamson *et al.*, 2001) will, therefore, need to be overcome before such resources can be considered a viable addition to existing information sources. Although computer illiteracy is diminishing as a new generation of people become the younger old, questions remain about whether this group of people will be able to continue to update their skills as they get older, and whether it is appropriate to develop technology solutions specifically for this age group, or to concentrate on accessible designs for the whole population (Capel *et al.*, 2007). Capel *et al.* (2007) argue that access, involvement and training need to be provided in everyday locations, and training needs to be closely related to people's physical, cognitive and information needs, and those of the particular communities where they live. In the meantime, the low level of awareness of newer sources of information, in particular NHS Direct, suggest that these services should at

least be promoted more actively to people with visual impairments. However, it will be important to acknowledge the impact that increased use of the Internet will have on the public-professional relationship, not only in terms of power issues, but also time efficiencies. Murray *et al.* (2003), for example, found that a substantial proportion of doctors thought that patients bringing information to their consultations resulted in the visit becoming less time efficient.

Although recognising individuals' preferences for different information providers, this research has indicated that there is considerable duplication of information across some of the different information providers, yet not all the information needs of visually impaired people are currently being met automatically. This is of particular concern and the findings of the interview study and audio diary study suggest that only those people most confident in asking questions are obtaining the information that they need and want. It is also possible that the sheer number of organisations and individuals involved in providing information to visually impaired people is overwhelming and, to some extent, confusing. There is, therefore, clearly a need for a more co-ordinated and targeted information service for visually impaired people.

This research has also demonstrated that various factors, in addition to the type, length and registration of visual impairment, have the potential to affect the information behaviour of visually impaired people. These factors, such as the presence of other health conditions and/or disabilities, individuals' acceptance of their visual impairment, and people's interactions with different information sources, need to be taken into consideration when designing information services for visually impaired people, as well as when undertaking research with this group of people. The subtle differences in the information behaviour of the two groups of people with visual impairments taking part in the interview study also provide additional support to Beverley *et al.*'s (2004) and Godber's (1999) suggestion that visually impaired people are not a homogeneous group, and should not be treated as such, for providing information.

This research has reaffirmed that a person's interaction with health and social care providers is clearly important in determining the extent to which a person's information needs are met and, subsequently, their involvement in the decision-making process, particularly regarding treatment options. A study of people with breast and colorectal

cancer by Beaver and Booth (2007) found that patients preferred to share or delegate decision-making to doctors, rather than make decisions themselves. This contradicts recent government drives to promote patient choice and decision making, being guided by, rather than led by, health professionals. This finding also conflicts with the findings here which seem to suggest that visually impaired people wanted to be more involved in the decision-making process through the provision of appropriate information. Perhaps this difference is due to the nature of the health condition under investigation; that is, cancers tend to be more life threatening, whereas visual impairments are more chronic conditions and, therefore, visually impaired people often have more time to make a decision. It is clear, however, that getting the right information at the right time is an essential pre-requisite of patient involvement in the decision-making process (Beaver and Booth, 2007). In addition, decision-making preferences need to be established on an individual basis to ensure that patients are involved in the decision-making process to the extent that they prefer (Beaver and Booth, 2007).

Finally, within this section it is helpful to refer back to Section 8.3 which considered in detail the application of two established information models (Moore, 2002 and Wilson, 1999) to the findings of this research. This analysis has provided a wider context for this research, as well as helped in our understanding of the health and information behaviour of people with visual impairments. As a result of this research, it has also been possible to validate and propose refinements to both information models. The identification of an additional 'intervening variable' relating to an individual's health characteristics, for example, suggests that there is potential to explore Wilson's (1999) model further in the context of the information behaviour of other groups, diseases and conditions. It would also be interesting to examine the information behaviour of people with visual impairments based on newer integrated models of human information behaviour, such as Spink and Cole (2006).

8.4.2 Meeting the health and social care information needs of people with visual impairments

It is not possible from this research to say definitely the extent to which the health and social care information needs of people with visual impairments are currently being met. However, a detailed study of local societies for the blind and partially sighted, one of the

key information sources for visually impaired people identified in the interview and audio diary studies, has started to highlight some of the gaps and overlaps in information provision. Local societies provide a wide range of information to visually impaired people about health and social care matters. On the whole, this information mirrors the clusters of information needs identified in the interview study and audio diary study. Although most of the information provided related to aids, adaptations and equipment, and health and social care services available to visually impaired people, it was interesting to find that some local societies also provided specific information about different eye conditions. The reasons behind this were not explored as part of this research, but it may be because visually impaired people are not readily obtaining the information they need and want about their eye condition from other sources, such as health care professionals. Local societies may, therefore, have a valuable role to play in reinforcing information received by visually impaired people at the time of diagnosis.

The high proportion of local societies with Internet access and using the Internet to seek health and social care information for their clients is worthy of further comment. This finding suggests that managers of local societies are beginning to recognise the benefits of using the Internet over traditional information sources on a variety of matters, including the availability and reviews of equipment for visually impaired people, and on the prognosis, diagnosis and treatment of rare eye conditions. Although, several managers referred to the importance of establishing the reliability and validity of web sites, some of the responses to the survey revealed that more education was still required in this area.

The need for a more co-ordinated and targeted information service for visually impaired people emerged from both the interview and audio diary studies. Swain *et al.* (2007) similarly found that there was a lack of co-ordination between information providers across geographical, sectoral and organisational boundaries, and rarely did an individual or an organisation take responsibility for providing information about the entire range of services available. This idea of an "integrated information service" for visually impaired people was explored in more detail in the survey of managers of local societies. On the whole, the concept was well-received. However, several managers clearly believed that they were already providing such a service; for example, by running eye information desks at local hospitals. Although most managers were able to identify barriers to putting such an information service into practice, most notably concerns about sharing personal

information, the majority of managers were also able to identify ways of overcoming these barriers and suggested additional facilitators, such as developing local and/or regional visual impairment strategies, and actively involving visually impaired people in shaping services.

Further work is clearly required in turning the concept of an “integrated information service” into a reality, but there definitely appeared to be an interest and willingness from the majority of local society managers taking part in this research. The views of managers and practitioners of the NHS, Social Care and other voluntary agencies are not yet known. However, recent government publications, such as the *Our Health, Our Care, Our Say* White Paper (Department of Health, 2006b), stress the importance of joint working and integrated information systems and are likely to drive developments like these. In addition, as noted elsewhere in this thesis, individuals do not tend to make the distinction between health and social care themselves (Lewis, 2001).

The scope and remit of such an “integrated information service” remains to be determined. For example, whether it would be feasible to operate such a system at a national or regional level, or whether it would be more appropriate for local agencies to work together more closely, both with each other, as well as with national bodies, such as the RNIB and NHS Direct. The latter approach would also build on the work of previous authors, such as The Smith and Williamson Group (1997), and Lomas (2000). However, with the predicted exponential increase in the number of visually impaired people over the next few years (Bosanquet and Mehta, 2008) and the acknowledgement of the beneficial effects of the provision of health and social care information to the public (Hall *et al.*, 1998; Fallowfield, 2001; Payne, 2002), the need to improve the efficiency and effectiveness of information provision and access to people with visual impairments will become increasingly important.

Although this research has not explored explicitly the role of librarians in both supporting and triggering visually impaired people to identify and specify their information needs (Attfield *et al.*, 2006), there is clearly potential for specialist information professionals to work alongside the different information sources identified here, such as health and social care professionals and local societies for the blind and partially sighted, to provide a value-added service and ensure that the information needs of visually impaired people are met.

To conclude this section, it is helpful to refer back to an old Social Services Inspectorate publication, *Signposts to Services* (Social Services Inspectorate, 1998). Although this looked at what local councils should do in order to provide better information to the public, its conclusions can be applied across the health, social care and voluntary sectors:

"Providing good information ... is more than just advertising. It helps people to understand what is available so that they can make informed choices. If they know about all the services on offer, their cost and who provides them, they can decide what they would find most helpful. The range of public services can be bewildering for potential service users. Information is the signpost that helps them to understand what is available and where it can be obtained. This helps people to retain control over their lives and maintain independence." (Social Services Inspectorate, 1998)

8.4.3 Audio diaries as a research method

In spite of the potential advantages audio diaries offer over other traditional research methods, such as interviews and questionnaires, audio diaries do not appear to be commonly used in the research literature. In fact, the study reported here is only the second one published using audio diaries with visually impaired people. The other study (Papadopoulos and Scanlon, 2002b) was considerably smaller involving only three visually impaired people making a diary over the course of a single day. This lack of uptake of audio diaries as a research method is surprising, given the strengths of the approach identified in this thesis, particularly the potential this method has to provide a more complete picture of the topic under investigation by allowing participants to tell their own stories. In addition, the approach was well-received by both the participants and the researcher, to the extent that participants took more ownership of, and interest in, the research.

It is possible that other researchers are simply not aware of this method, that they have concerns about how to use the approach in practice, that they think that the recruitment of participants might prove difficult due to the additional time commitments, and/or they have concerns about how to analyse the emerging lengthy and largely unstructured transcripts. The last point is certainly one which the researcher herself struggled with. Although she tried to introduce some structure by asking participants to state the date and time at the start of each diary entry and by providing guidance notes, some participants felt that even this approach was too restrictive. As Bowling (2002) emphasises, however, it is important

to achieve the right balance of structure when using diaries as a research method to make the subsequent analysis manageable.

Overall, the researcher believes that, at least in this case study, the strengths of audio diaries far outweighed the weaknesses. By supplementing the interview study with an audio diary study, it was possible to gain greater insights into the information needs and behaviour of visually impaired people. The researcher is of the opinion that audio diaries have the potential to provide an effective means to collect data not only from older visually impaired people, but also from a wide range of other people, particularly in emancipatory research studies (Beresford and Campbell, 1994).

8.4.4 The effective involvement of visually impaired people in the design and conduct of research

Another key feature of this research was the active involvement of visually impaired people in the design of the different studies. Chapter 7 described how the involvement of visually impaired people in two main ways (via local visual impairment support groups, and the recruitment of five visually impaired advisors) resulted directly in seven major changes being made to the course of this research. Most of these changes related specifically to the scope of the research and the research design and methods. Although it is not possible to ascertain whether these changes would not ultimately have been made without the visually impaired people's input, the researcher believes that these changes did lead to the research being more practical and accepted by participants in the individual studies. This was illustrated by the researcher's and one of the visually impaired advisor's close relationship with a local society for the blind which resulted in changes being made to the way in which the eye information desk operated at the hospital. This was in direct response to the findings of the interview study and audio diary study.

The evaluation of the public involvement elements of this research have yielded some suggestions about the involvement of visually impaired people in future research studies, as well as contributed to the wider public involvement literature and debate (e.g., Boote *et al.*, 2002). For example, it is important to achieve an appropriate level, type and frequency of consultation with people. The majority of contact with the advisors in this research was by email or over the telephone. However, as the findings of this evaluation indicate, this

approach is not always appropriate and consideration should be given to holding face-to-face meetings at key stages in the research. If such meetings are held, it will be important to consider practical issues for visually impaired people, such as lighting, layout of the room, *etc.* In this research, the follow-up interviews with advisors indicated that contact every three to four months was too infrequent. A balance must, therefore, be achieved between consultation being regular enough to maintain interest, but not being too frequent so as to be onerous. The job description (Hanley *et al.*, 2004), or perhaps more appropriately called 'role profile', proved useful in this research and the creation of such documents should be encouraged in other studies. It was clear from this evaluation that the visually impaired advisors would have liked to have been more involved in the research, perhaps by actually undertaking some of the research themselves as well. Although there are potential constraints of doing this within the context of studying for a Ph.D., users should be consulted at the start of a project about the extent to which they want to get involved; for example, whether they would like to undertake interviews, *etc.* For Ph.D. research, it might be possible to involve users more in identifying participants and the analysis and interpretation of the findings of the research.

Finally, the evaluation of this aspect of the research has indicated that the active involvement of visually impaired people has benefited the research, the researcher and the advisors. Ideally not only should the users contribute to the research in terms of their contacts, direct experience and/or prior research experience, but, by being involved, they should also received something in return, be that ownership of the findings, research experience, or simply being able to share their experiences with someone else.

8.5 Trustworthiness of the Research

It is important to reflect on the validity and reliability of the research as a whole in order to have confidence in the findings. The rest of this section considers the research in terms of the four areas (credibility, transferability, dependability and confirmability) identified by Lincoln and Guba (1985), and this helps to highlight the strengths and limitations of the research.

8.5.1 Credibility

Overall, the findings reported here are credible and believable. This is illustrated by the fact that both the participants and visually impaired advisors were in agreement with the summaries of the findings sent to them after each of the studies. In addition many of the key findings reported here are either in accordance with or expand upon the existing literature in the field.

8.5.2 Transferability

It could be argued that the interview study and audio diary study were based on small, self-selecting samples, and it is, therefore, possible that the people taking part in this research were not representative of the visually impaired population as a whole. However, qualitative research is not designed to be generalisable (Lincoln and Guba, 1985), but instead enables a detailed insight into the needs and behaviour of a small sample of people. The fact that two separate studies (the interview study and audio diary study) were undertaken with older visually impaired people and that similar findings were obtained suggests that the findings are applicable to other older people with visual impairments. Similarly, the fact that the findings could be interpreted within the context of two different information models indicates that the findings may be transferable not only to other visually impaired people, but also possibly to other groups of people with different chronic health conditions, such as arthritis, diabetes, *etc.* In terms of the survey of local society for the blind and partially sighted managers, it is important to note that not all local societies are members of NALSVI and, therefore, the views of some organisations may have been overlooked. However, a very high response rate (84%) was achieved to this survey. Finally, in discussions with the visually impaired advisors to this research, there was agreement about the overall findings, thereby suggesting that the findings are transferable.

8.5.3 Dependability

It is difficult to be certain whether similar findings would emerge if this research was repeated. However, the researcher has been careful to clearly document all of the stages in the research process, including the search strategy, the interview topic guide, the framework emerging from the analysis of the interview and audio diary studies, the

questionnaire used with the local society managers, and the job description for the visually impaired advisors. Therefore, theoretically someone else could use the same materials to address the same research questions. Where differences may arise is in terms of the analysis of the qualitative research. This is because individuals view the world in different ways and the researcher's own social identity and background (Gerrish and Lacey, 2006) may have impacted on the analysis undertaken. Ideally, analysis should be done by more than one person. However, this has not been possible here due to the research being undertaken as part of a Ph.D. The interpretation of the findings has been shared and discussed with the visually impaired advisors to this research, however, thereby providing an additional means of verification.

8.5.4 Confirmability

Any kind of research is subject to some forms of bias (Gerrish and Lacey, 2006). For example, the researcher selected this research topic partly in response to her grandmother being diagnosed with AMD and it is, therefore, possible that her personal experience has impacted on the design and interpretation of the research. Similarly, the researcher was very interested about the novel aspects of this research, in particular the audio diary study and the underlying public involvement ethos. This will inevitably have unconsciously impacted on her evaluation of these components of the research. In order to address these potential biases, the researcher has taken care to ensure that the findings presented are truly representative of the views expressed by participants and that quotations have been used from a wide range of participants, rather than depending on a few key individuals. In addition, as discussed in Section 8.2.1, a variety of methods have been used which have helped to confirm the findings from each of the studies individually. The initial findings from each of the studies were also fed back to participants for checking and verification.

Overall, the research approach has been trustworthy and considerable attempts have been made to address or acknowledge any potential limitations in the research design and analysis. We can, therefore, have confidence in the final conclusions and implications for practice and future research relating to the health and social care information needs and behaviour of people with visual impairments which are presented in the next chapter.

CHAPTER 9. CONCLUSIONS AND IMPLICATIONS

9.1 Introduction

The research presented in this thesis has been predominantly exploratory in nature and, as discussed in Chapter 8, has substantially increased our knowledge and understanding of the health and social care information needs of people with visual impairments. By examining the findings in the context of two established information models, our theoretical understanding of the information behaviour of two groups of visually impaired people (people with an age-related visual impairment and people with a visual impairment since birth or early childhood) has been enhanced. In addition, the research has clearly highlighted the potential value of audio diaries as a research method with a wide range of people. Finally, this research has added to the growing debate on public involvement in research by evaluating the impact of actively involving visually impaired people in this research. The purpose of this chapter is to draw together the major findings across all of the phases of research presented here, and to highlight some of the key implications for practice and future research.

9.2 Conclusions

In order to draw firm conclusions, it is helpful to return to the original research questions posed at the start of this research.

9.2.1 What are the major health and social care information needs of people with a visual impairment?

This thesis provides a clearer understanding of the major health and social care information needs of people with a visual impairment and builds upon previous research in the field, in particular Beverley *et al.* (2004). For the visually impaired participants taking part in this research, these information needs fall into one of eight categories: the eye condition; health and social care services and facilities; aids, adaptations and equipment; general health care; benefits and money; mobility; housing and accommodation; and employment, education and training. While some of these information needs are currently

met by information providers, it is clear that other information needs remain unmet. It is also evident that simply providing information in an accessible format is not always sufficient: the timing, quantity, quality and support mechanisms available are all also important.

9.2.2 What information sources do people with a visual impairment use to obtain information about health and social care matters?

People with visual impairments use a wide variety of sources to obtain the information they require about health and social care matters. These include health care professionals; social care professionals; societies, organisations and support groups; family and friends; the mass media and the Internet. The relative importance of these different information sources appears to depend on the individual, but health care professionals and the local society for the blind emerged as the major sources of information for most participants in this research. However, it was also evident that there was considerable duplication of information across the different information providers, and that greater co-ordination and targeting of information was needed.

9.2.3 What factors (e.g., types of visual impairment, length of diagnosis, etc.) affect the health and social care information behaviour of people with a visual impairment?

This research has indicated that several factors (similar to Wilson's (1999) 'intervening variables') have the potential to affect the information behaviour of people with a visual impairment accessing health and social care information. These range from health factors, such as the type, length and registration of visual impairment, and the presence of other health conditions and/or disabilities, to personal factors, such as an individual's acceptance of their visual impairment. The findings of the interview study presented in Chapter 4, for example, suggest that there are subtle differences in the information behaviour of people with an age-related visual impairment and people with a visual impairment since birth or early childhood, and confirms that visually impaired people cannot be treated as a homogeneous group with respect to information provision.

9.2.4 To what extent can current developments in information provision (e.g., NHS Direct and the Internet) help to meet the health and social care information needs of people with a visual impairment?

Newer sources of information, in particular NHS Direct and the Internet, have the potential to improve access to health and social care information to visually impaired people. However, these sources are still in their infancy and various barriers (e.g., availability and cost of specialist accessibility software) must be overcome before they can be considered a viable addition to existing information sources. The low level of awareness of NHS Direct amongst participants in this research, both visually impaired people and managers of local societies for the blind and partially sighted, suggests that this service needs to be promoted more actively not only to these groups, but also to the wider public.

9.2.5 Can two established information models (Wilson, 1999 and Moore, 2002) explain the information behaviour of visually impaired people accessing health and social care information?

Analysing the results of the interview and audio diary studies within the context of Moore's (2002) model of social information need and Wilson's (1999) model of information behaviour has contributed to an increased understanding of the information behaviour of people with visual impairments accessing health and social care information behaviour. On the whole, the findings are in accordance with both models, but this research has enabled further refinements to be put forward, most notably an ordered hierarchy of Moore's (2000) clusters of information needs, and the addition of an additional 'intervening variable' to Wilson's (1999) model, relating to an individual's health characteristics (type, degree and length of visual impairment and presence of other health conditions and disabilities).

9.2.6 What are the strengths and weaknesses of using audio diaries as a research method with older visually impaired people?

This research has demonstrated that audio diaries can offer various advantages over traditional data collection methods, such as interviews and questionnaires, for older people with visual impairments. Most notably, participants seemed to genuinely enjoy making their audio diaries and took great ownership of, and interest in, the research. From the

researcher's point of view, the diaries helped to give an indication of the frequency and context of events which contributed to an increased understanding of the information behaviour of participants. However, this approach was not without its weaknesses, in particular, the long commitment required from participants and the restrictions of employing a semi-structured framework for recording diary entries. It is anticipated that these issues can be explained further and addressed in future research, not only with visually impaired people, but also with other groups of people, particularly those experiencing chronic health conditions, such as arthritis and diabetes.

9.2.7 To what extent do local societies for the blind and partially sighted meet the health and social care information needs expressed by visually impaired people taking part in this research?

On the whole, local societies for the blind and partially sighted do appear to have the potential to provide most of the information that the interview and audio diary participants expressed a need for. However, the findings from this research indicate that the information provided mainly relates to aids, adaptations and equipment, and health and social care services available to visually impaired people. The type of information provided also varied considerably from one society to another. Local societies clearly have an important role to play in meeting the health and social care information needs of people with a visual impairment, particularly in terms of reinforcing information received from other sources, and signposting people to other services and sources of information. The challenge will be for local societies to work more closely with other agencies, such as the NHS and social care providers, to reduce duplication of effort and co-ordinate health and social care information provision.

9.2.8 What do managers of local societies perceive to be the major barriers and facilitators to providing an integrated information service to visually impaired people across the health, social care and voluntary sectors?

On the whole, the concept of an "integrated information service" for visually impaired people across the health, social care and voluntary sectors, was well-received by managers of local societies for the blind and partially sighted. The major barriers identified to putting this in to practice related to concerns about sharing personal information,

conflicting priorities of different organisations, as well as budget constraints. Many of the barriers cited could be addressed by an extensive multi-disciplinary training programme covering issues, such as the Data Protection Act, change management, etc. In addition, managers participating in the survey were able to highlight other key facilitators, such as developing local and/or regional visual impairment strategies, and actively involving visually impaired people in shaping services.

9.2.9 What impact did actively involving visually impaired people in this research have on the overall design and outcomes?

Involving visually impaired people in the design of this research has proved a very useful and interesting experience, both from the researcher's and advisors' point of view. As noted in Chapter 7, changes were made in seven areas of the research in direct response to feedback from visually impaired people. Six of these areas related specifically to the scope of the research and the research design and methods; for example, the inclusion of social care information, as well as health care information; and the adoption of individual face-to-face interviews in preference to focus groups. It is thought that these changes resulted in the research being more practical and accepted by participants, as illustrated by the number of implications for practice summarised below.

9.3 Implications for Practice and Policy

This research has identified several implications for practice. These mainly relate to ensuring that providers of information automatically provide health and social care information in a person's preferred format and that they recognise people's individual needs and preferences; as well as improving the co-ordination, targeting and sharing of information by different organisations. Local societies for the blind and partially sighted have an important role to play in this process and in shaping local, regional or national integrated information services for visually impaired people. This has already been demonstrated in practice by a local society responding directly to the findings of the interview and audio studies and taking over the co-ordination of the eye information desk at the hospital.

In addition, there is a need to promote newer information sources, such as NHS Direct and the Internet, more effectively to both providers of information, as well as visually impaired people themselves. People with visual impairments also need to be more engaged in the design of services, particularly in terms of identifying the most appropriate time for information to be provided by health and social care professionals. There are training implications associated with implementing these recommendations; in particular there is a need to educate staff further about the Data Protection Act so that information about visually impaired people can be efficiently and effectively shared between different agencies. Other training needs relate to the use of the Internet and basic critical appraisal skills, as well as how service providers can effectively involve the public in service delivery.

9.4 Implications for Future Research

Various implications for further research have also emerged from the findings of this research. Firstly, it will be important to test the generalisability of the interview study and audio diary study findings by undertaking a large-scale quantitative study of the health and social care information needs of visually impaired people. Ideally this study should focus on one particular group of visually impaired people, such as people with AMD. Secondly, it would be helpful to repeat the audio diary study with a sample of newly diagnosed visually impaired people to establish if this addresses some of the weaknesses identified here. Thirdly, further work examining Wilson's (1999) revised model of information behaviour in the context of other health information research would be beneficial in terms of determining whether the additional 'intervening variable' identified relating to a person's health characteristics exists for other conditions and disabilities. It would also be interesting to re-examine the data from the interview and audio diary studies within the context of more recently published human information behaviour models, such as Spink and Cole (2006). Finally, future research in this field should, where possible, involve people with visual impairments in both designing and conducting the research. Such an approach is likely to result in more reliable and relevant research, but also prove to be an enjoyable experience for everyone involved.

This chapter, therefore, concludes this thesis by summarising the main findings in relation to the original research questions and, in doing so, highlights the wider implications of this thesis in terms of future practice, policy and research.